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ABSTRACT

This White Paper by the National Council on Disability urges the support and participation of American policymakers and organizations representing people with disabilities in the drafting of an international human rights treaty specifically addressing the rights of people with disabilities. Following an executive summary and an introductory section, the first section provides background information on disability law in the United States and human rights for people with disabilities within the international human rights system. The fourth section offers suggestions for addressing the human rights of people with disabilities in sections urging a paradigm shift in which "needs" become rights and discussion of universality and international human rights law. The fifth section proposes an international convention on the rights of people with disabilities with discussion of transformative participation in an international human rights treaty-making process, promoting institutional shifts through the adoption of an international convention on the rights of people with disabilities, and the role of legally binding obligations. The following section considers issues in adopting an international convention that especially strengthens the advocacy capacity of people with disabilities and their allies, ensures constructive U.S. participation, and combats treaty fatigue. The final section offers recommendations and future directions. Appended are a glossary of international law terms and the mission statement of the National Council on Disability. (DB)

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A White Paper

Understanding the Role of an International Convention on the Human Rights of People with Disabilities

An analysis of the legal, social, and practical implications for policy makers and disability and human rights advocates in the United States

National Council on Disability

June 12, 2002

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I. Executive Summary

The Problem

People with disabilities constitute a sizable global population, yet the often appalling human rights condition experienced by this community has remained largely unaddressed. Although the human rights system encompasses the principles of equality and non-discrimination, people with disabilities are commonly the subjects of de jure and de facto discrimination on a daily basis. This discrimination occurs in a range of arenas, including the workplace, schools, health care facilities, government, recreational facilities, and many more societal contexts. As a result of discrimination, segregation from society, economic marginalization, and a broad range of other human rights violations, people with disabilities have consistently been excluded from the decision-making fora where positive changes in law and policy can be developed and implemented. While some governments and societies have adopted a social inclusion and a rights-based approach to disability issues, many more rely on charity models of assistance or a narrow medical model that focuses on finding medical "solutions" to limitations caused by a disability and ignores the need to address the vast array of limitations created and imposed by discrimination, exclusion, and ignorance.

Existing Protections

Although such domestic legislation as the Americans with Disabilities Act (ADA) does indeed expand legal protections for people with disabilities and open up opportunities for their full participation in society, the promise of the ADA remains unfulfilled. In his launching of the New Freedom Initiative in February 2001, President George W. Bush acknowledged his commitment to "tearing down the remaining barriers to equality that face Americans with disabilities today" and recognized that "significant challenges remain for Americans with disabilities in realizing the dream of equal access to full participation in American society" to create "a nation where no one is dismissed or forgotten." In the international human rights legal framework, people with disabilities are, for all practical purposes, invisible, despite the fact that

all human beings are entitled to the full panoply of human rights protections. Disability is persistently marginalized as a human rights issue within the United Nations system and in the work of international non-governmental organizations, including human rights organizations. Although disability has been specifically addressed in some existing human rights documents that do add content to the human rights field, such provisions are for the most part not housed in a treaty, nor are they widely regarded as having attained the status of binding law. Moreover, these documents have not effected integration of disability into the program areas of most international institutions. In countries where national legislation to protect the rights of people with disabilities is particularly weak, or even non-existent, self-advocacy efforts are further complicated by the lack of a globally recognized set of standards.

Arguments in Favor of a Convention

The current effort to secure the adoption of an international convention on the human rights of people with disabilities has much to offer. The most significant advantages include (i) providing an immediate statement of international legal accountability regarding disability rights; (ii) clarifying the content of human rights principles and their application to people with disabilities; (iii) providing an authoritative and global reference point for domestic law and policy initiatives; (iv) providing mechanisms for more effective monitoring, including reporting on the enforcement of the convention by governments and non-governmental organizations, supervision by a body of experts mandated by the convention, and possibly the consideration of individual or group complaints under a mechanism to be created by the convention; (v) establishing a useful framework for international cooperation; (vi) providing a fair and common standard of assessment and achievement across cultures and levels of economic development; and (vii) providing transformative educative benefits for all participants engaged in the preparatory and formal negotiation phases and for the public as countries consider ratification of the convention.

Whereas the provisions of an international human rights convention for people with disabilities will serve to articulate specific rights and provide machinery for monitoring

compliance with obligations, the transformative nature of the treaty-making process itself can also generate an array of important benefits. These benefits include raising the general public's awareness about the human rights of people with disabilities; highlighting abuses of those rights; further developing the knowledge-base of governmental and non-governmental participants; providing the stimulus for extensive programmatic developments; offering capacity-building opportunities for disability groups as a result of increased global focus on their issues; and improving data collection.

Future Directions

The momentum for the development of an international convention on the human rights of people with disabilities already exists, having been given impetus by the adoption of a UN General Assembly resolution, initiated by Mexico, calling for "a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities." That step builds on significant efforts undertaken in recent years by Ireland in support of such a convention. For a convention to be truly effective, it must represent the aspiration and experience of the people it seeks to protect. Consistent with the United Nations "Standard Rules on the Equalization of Opportunities for People with Disabilities," people with disabilities should be recognized as having a right to participate in drafting legal standards that will affect their ***human rights***. For the momentum generated by the United Nations General Assembly to be productively maintained and used, the process by which the convention is developed must be fully participatory and inclusive of people with disabilities, including the most marginalized groups. Different disability groups have somewhat different experiences and legal needs, and the full participation of a broad array of consumer-led disabilities groups—including organizations of people with mental, physical, and sensory disabilities—is essential at the international level. People with disabilities must ensure that the provisions of a treaty consist not of vague non-discrimination concepts but of clear principles that seek to recognize and counter multiple forms of discrimination and empower people with disabilities in such areas as public life and political representation; participation in decision-making in all areas,

including, but not limited to, legal and administrative contexts; and access to education, health care, and sport and culture. Members of the global disability community have much to gain from the active participation of their American counterparts, and, in turn, Americans stand to benefit from lending their voice to the convention dialogue.

II. Introduction

A. The Global Human Rights Condition of People with Disabilities

As a group composed of some 600 million people worldwide, of whom approximately 80 percent live in developing countries, people with disabilities are a sizable global population.[1] More compelling, however, than the sheer magnitude of this population, is the appalling lack of respect for even the most basic human rights of people with disabilities in both the developed and the developing world. As the first UN Special Rapporteur on Disability, Leandro Despouy, observed in 1991:

> [People with disabilities] frequently live in deplorable conditions, owing to the presence of physical and social barriers which prevent their integration and full participation in the community. As a result, millions of children and adults throughout the world are segregated and deprived of virtually all their rights and lead a wretched, marginal life.[2]

Access to housing, education, health care, non-exploitative employment, mobility in the built environment, and general social contact are of fundamental importance to all human beings. Yet millions of people with disabilities around the world are systematically denied access to the resources necessary to meet these basic needs, resulting in extreme poverty, social exclusion, and poor health. As is true with all socially disenfranchised and economically disadvantaged groups, people with disabilities generally have little or no influence in the public policy process or the decisions that affect their daily struggle for survival.

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[1] *Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities*, Third Committee, 56 Sess., Agenda Item 119(b), U.N. Doc. A/C.3/56/L.67/Rev.1 (28 Nov. 2001). Existing disability data is woefully inadequate, with published estimates of national, regional, and global populations of people with disabilities being highly speculative. The United States Agency for International Development (USAID) estimates the global population of people with disabilities to be 10 percent or more, and the Roeher Institute in Toronto, Canada, estimates the global population to be 13 to 20 percent. *See* Robert L. Metts, *Disability Issues, Trends and Recommendations for the World Bank*, DISCUSSION PAPER NO. 0007, 6 (Feb. 2000); MARCIA ROUX, ENABLING THE WELL-BEING OF PERSONS WITH DISABILITIES 2 (Roeher Institute 1998).

[2] Leandro Despouy, Special Rapporteur, *Final Report*, ¶ 3, U.N. Doc. E/C4/Sub2/1991/31 (12 July 1991).

Driving the legal and political decisions that result in this human rights crisis is the underlying attitude that people with disabilities have intrinsically less value because of their disabilities. That attitude is a double-edged sword. Not only does it influence the social and legal structures that affect—and often disempower—people with disabilities, but it has a direct impact on the people with disabilities themselves. Social psychologists have documented the manner in which oppressed groups who have been systematically denied power and influence in society often internalize negative messages about their abilities and come to accept them as their "truth."[3] Members of the disability community have illustrated the impact of this cycle in compelling personal accounts of disability oppression.[4] Internalized oppression works in combination with economic and social contexts and serves to restrict options that people generally perceive as open to them and legitimate for them.[5]

Ann Elwan, in her World Bank–sponsored study on poverty and disability, estimates that people with disabilities may account for one out of every five of the world's poorest people. She finds the following:

> Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level than the non-disabled population, and they are less likely to have savings and other assets. ...The

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[3] C. Kelly, M-H Keany & Robert L. Glueckauf, *Disability and Value Change: An Overview and Reanalysis of Acceptance of Loss Theory*, 139; and Ruth Torkelson Lynch & Kenneth R. Thomas, *People with Disabilities as Victims: Changing an Ill-Advised Paradigm*, 212, *in* THE PSYCHOLOGICAL & SOCIAL IMPACT OF DISABILITY (Robert P. Marinelli & Arther E. Dell Orto eds., Springer Publishing Company 1999).

[4] *See generally* NANCY MAIRS, WAIST-HIGH IN THE WORLD: A LIFE AMONG THE DISABLED (Beacon Press 1997); ROBERT MURPHY, THE BODY SILENT (Henry Holt 1987); CONNIE PANZARINO, THE ME IN THE MIRROR (Seal Press 1994); RUTH SIENKIEWICZ-MERCER & STEVEN B. KAPLAN, I RAISE MY EYES TO SAY YES (Whole Health Books 1989); DONNA WILLIAMS, NOBODY, NOWHERE: THE EXTRAORDINARY AUTOBIOGRAPHY OF AN AUTISTIC (Avon Books 1992); DONNA WILLIAMS, SOMEBODY SOMEWHERE: BREAKING FREE FROM THE WORLD OF AUTISM(Times Books 1994); IRVING KENNETH ZOLA, MISSING PIECES: A CHRONICLE OF LIVING WITH A DISABILITY (Temple Univ. Press 1983).

[5] *See, e.g.*, H. JACKINS, THE RECLAIMING OF POWER (1983); D. HUTCHINSON & C. TENNYSON, TRANSITION TO ADULTHOOD (Further Education Unit, 1986) (discussing disability oppression in the context of childhood); G. Pheterson, *Alliance Between Women: Overcoming Internalized Oppression and Internalized Domination, in* BRIDGES OF POWER: WOMEN'S MULTICULTURAL ALLIANCES (A. Albrecht & R.M. Brewer, eds., New Society Publishers 1990). *See also* INTERNATIONAL COUNCIL ON HUMAN RIGHTS POLICY, THE PERSISTENCE AND MUTATION OF RACISM 20-21 (2000) (discussing the ways in which those oppressed by racism respond to their marginalization in society).

links between poverty and disability go two ways—not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability.[6]

Because discrimination, lack of access to the built environment, and other factors frequently exclude people with disabilities from the workforce, they are unable to contribute to their own financial security, and that puts them in danger of becoming impoverished, if they do not live in poverty already. In all nations, people with disabilities earn less from paid employment than their counterparts, but even in countries with legal protections against employment discrimination, most people with disabilities are unemployed. In the United States, workplace harassment of people with disabilities is commonplace, and biases can be particularly severe with regard to people with "hidden disabilities," such as mental disabilities.[7] Pervasive ignorance among employers frequently leads to people with disabilities being rejected for employment because potential employers mistakenly assume these potential employees will not be able to fulfill job requirements or reasonable accommodations will be extensive and costly.[8] Because people who are unemployed cannot contribute tax revenues to the government, this situation reinforces the stereotype of people with disabilities as a burden on society. Consequently, programs to support people with disabilities, where they exist at all, are commonly based on the "charity" model of assistance over more empowering and positive models that can help to break, rather than reinforce, the cycle of poverty and dependence.[9]

A person with a disability who is also member of another disadvantaged group will frequently find himself/herself subject to discrimination on multiple levels. For example, studies

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[6] Ann Elwan, *Poverty and Disability: A Survey of Literature*, WORLD BANK SOCIAL PROTECTION DISCUSSION PAPER NO. 9932, iv (Dec. 18, 1999).

[7] DISABILITY RIGHTS ADVOCATES, DISABILITY WATCH: THE STATUS OF PEOPLE WITH DISABILITIES IN THE UNITED STATES 26 (1997).

[8] *Id.* It has been reported that "of the changes made by hundreds of businesses [in the United States] to create a more user-friendly environment for disabled people, it was found that well over half of the adjustments cost less than US $100 each." DISABILITY RIGHTS ADVOCATES, STATUS OF THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES IN CENTRAL EUROPE 5 (2001).

[9] DISABILITY RIGHTS ADVOCATES, *supra* note 8, at 2.

show that people with disabilities are less likely than others to receive education and often leave school with fewer skills and qualifications.[10] For disabled women and girls, however, as research undertaken by the Economic and Social Commission for Asia and the Pacific (ESCAP) indicates, gender discrimination presents additional obstacles to educational opportunities.[11] The problem of compound discrimination for people with disabilities can be found in every country of the world regardless of its economic or political situation. *Lift Every Voice*, a report by the National Council on Disability on issues that affect people with disabilities from diverse racial and cultural backgrounds in the United States, reported that "people with disabilities from diverse cultural communities not only experience poverty and disability at a disproportionately higher rate, they also face language, cultural and attitudinal barriers that significantly impede their access to resources and accommodations."[12] In developing nations, the problem is rooted as much in the actions of developed nations as in local conditions and attitudes. Despite the fact that 51 percent of people with disabilities are women, "international development programmes rarely address the needs of disabled women or include them in community development ventures."[13] A report by Mobility International USA on gender and disability found that "most [development] organizations do not collect data showing the extent to which people with disabilities, in particular women and girls with disabilities, participate in the development assistance process."[14] The lack of interest in these issues by leading institutions funded and led by developed nations sets a poor example for countries that rely on the aid of developed nations, especially emerging democracies and societies struggling to rebuild their social structure in a post-conflict setting.

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[10] Elwan, *supra* note 6, at 11.

[11] ESCAP, *Hidden Sisters: Women and Girls with Disabilities in the Asian and Pacific Region*, U.N. Doc. ST/ESCAP/1548 (1995), available at: <http://www.unescap.org/decade/wwd1.htm>.

[12] NATIONAL COUNCIL ON DISABILITY, LIFT EVERY VOICE: MODERNIZING DISABILITY POLICIES AND PROGRAMS TO SERVE A DIVERSE NATION 27 (Dec. 1, 1999).

[13] DISABILITY AWARENESS IN ACTION, DISABLED WOMEN 5 (1997).

[14] TINA SINGLETON ET AL., GENDER AND DISABILITY: A SURVEY OF INTERACTION MEMBER AGENCIES ix (Mobility International USA 2001).

The status of people with disabilities is marked not only by exclusion and lack of equal access to resources—in other words, the absence of attention to their rights—but also by deliberate and active measures taken against them. Some such measures are legally supported elements of a strategy to "deal" with disability, such as involuntary institutionalization. People with disabilities are subject to a variety of human rights abuses, including forced abortion and sterilization[15] and psychiatric drugging.[16] Other actions are tolerated or overlooked despite being illegal, such as physical and mental abuse and gross neglect. Violence against people with mental disabilities in institutions insulated from public scrutiny often goes unaddressed.[17] For example, in Kosovo, Mental Disability Rights International (MDRI) found that despite extensive international funding for civil society and human rights, no program has been established to protect the rights of women or other vulnerable groups from sexual and physical abuse in institutions.[18] Other reports issued by MDRI describe the "inhuman and degrading conditions" of people in institutions in

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[15] According to the February 2000 US State Department Human Rights Report, in 1997, the Government of Japan acknowledged that some 16,500 women with disabilities were sterilized without their consent between 1949 and 1992. The Government rejected calls by the disability community for compensation on the basis that the procedures were legal according to domestic law. Report available at: <http://www.state.gov>.

[16] *See* NATIONAL COUNCIL ON DISABILITY, FROM PRIVILEGES TO RIGHTS: PEOPLE LABELED WITH PSYCHIATRIC DISABILITIES SPEAK FOR THEMSELVES, 12 (Jan. 20, 2000). (Stating that nearly two-thirds of the states have passed involuntary outpatient commitment [IOC] laws that involve court-ordered treatment [almost always medication] for people who are not physically dangerous to themselves or others. As a result, more people who find these medications debilitating are being forced to take them under court order.)

[17] As noted by Degener and Quinn, people with disabilities who are institutionalized are often unable to protect themselves against abuse or seek appropriate redress. They are often unaware of their rights, and even if they are aware, they are frequently isolated from those in a position to assist them. THERESIA DEGENER & GERARD QUINN ET ET AL., HUMAN RIGHTS ARE FOR ALL: A STUDY ON THE CURRENT USE AND FUTURE POTENTIAL OF THE UN HUMAN RIGHTS INSTRUMENTS IN THE CONTEXT OF DISABILITY §6.1 (draft Feb. 2002). *See also* Arlene S. Kanter, *Abandoned but not Forgotten: The Illegal Confinement of Elderly People in State Psychiatric Institutions*, 19 N.Y.U. REV. L. & SOC. CHANGE 273 (1991/92).

[18] MENTAL DISABILITY RIGHTS INTERNATIONAL, NOT ON THE AGENDA: HUMAN RIGHTS OF PEOPLE WITH MENTAL DISABILITIES IN KOSOVO (in press, Spring 2002). The gross mistreatment of women in institutions is widespread and includes the practice of forced sterilization and abortion, rampant sexual abuse by staff and patients, arbitrary denial of parental rights and an array of coercive treatments. *See also* Eric Rosenthal, *International Human Rights Protections for Institutionalized People with Disabilities: An Agenda for International Action*, *in* LET THE WORLD KNOW: A REPORT OF A SEMINAR ON HUMAN RIGHTS AND DISABILITY 68, 70 (Marcia Rioux, ed., Almåsa, Sweden, November 5-9, 2000). For a more detailed description of human rights abuses against women with disabilities, see MENTAL DISABILITY RIGHTS INTERNATIONAL, VIOLENCE, WOMEN AND MENTAL DISABILITY (1998) available at: <http://www.MDRI.org>.

Uruguay, Hungary, Russia, and Mexico.[19] In Mexico, MDRI cites the "unhygienic conditions of detention"; the excessive use of "physical restraints"; the lack of adequate food, water, clothing, and medical care; the "lack of privacy and dignity" for patients; and even instances of patients freezing to death.[20] To be sure, such conditions are by no means limited to the countries cited in these referenced reports.

An improvement in the human rights condition of people with mental, physical, and sensory disabilities is urgently needed in all nations, not only developing nations or nations devastated by years of conflict. Even in the most technologically advanced nations, people with disabilities confront the most basic violations of their rights in attempting to exercise their right to vote. In the 2000 elections in the United States, in at least 18 states, disabled voters found inaccessible polling places, confusing ballots, and a lack of privacy and independence in voting.[21] For instance, at a polling station in New York, disabled voters found access ramps "locked and unavailable,"[22] while in California, a lack of portable voting booths forced one disabled voter to

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[19] *See generally* MENTAL DISABILITY RIGHTS INTERNATIONAL, HUMAN RIGHTS & MENTAL HEALTH: MEXICO (2000), CHILDREN IN RUSSIA'S INSTITUTIONS: HUMAN RIGHTS AND OPPORTUNITIES FOR REFORM (1999), HUMAN RIGHTS & MENTAL HEALTH: HUNGARY (1997), HUMAN RIGHTS & MENTAL HEALTH: URUGUAY (1995). These reports, as well as a pending report on the human rights of people with disabilities in Kosovo, are available at <http://www.MDRI.org>.

[20] HUMAN RIGHTS AND MENTAL HEALTH: MEXICO, *supra* note 19, at 13-41. For example, MDRI found that nearly half the people in a ward in Sayago were left tied to their wheelchairs, because staff shortages left them with insufficient personnel to supervise the residents. As a result, residents were not only treated without dignity, but they were also placed in real danger of developing extensive muscle atrophy (aggravating their existing disabilities) and life-threatening bedsores. *Id.* at 19.

[21] Kay Schriner, *USA: Votes of Disabled People among 'Epidemic of Disappearing Votes'*, DISABILITY WORLD, Issue No. 10 (Sept-Oct. 2001). Voters in Lee County, Iowa, found every one of its 23 polling stations inaccessible to disabled voters. DEMOCRATIC INVESTIGATIVE STAFF, HOUSE COMMITTEE ON THE JUDICIARY, HOW TO MAKE OVER ONE MILLION VOTES DISAPPEAR: ELECTORAL SLIGHT OF HAND IN THE 2000 PRESIDENTIAL ELECTION 53 (Aug. 20 2001), available at <http://www.house.gov/judiciary_democrats/electionreport.pdf>. Accessibility to polling places and ballot secrecy has been prioritized in President Bush's New Freedom Initiative. The Initiative recognizes that "20,000 of the Nation's more than 120,000 polling places are inaccessible to people with disabilities." NEW FREEDOM INITIATIVE 22 (February 2001). In addition to addressing voting technology, there are a vast range of other challenges posed by Electronic and Information Technology (E&IT) as well as documented in a report issued by the National Council on Disability. NATIONAL COUNCIL ON DISABILITY, THE ACCESSIBLE FUTURE (June 21, 2001).

[22] DEMOCRATIC INVESTIGATIVE STAFF, *supra* note 21, at 6. In Colorado, some disabled voters found the access ramps blocked by cones used to direct able-bodied voters. *Id.* at 32.

have his personal care assistant vote on his behalf, thus depriving him of his right to independence and privacy.[23] In other cases, inadequate training of polling staff led to violations of disabled voters' rights. Some staff denied the existence of voter accessibility laws (saying instead that disabled voters could use the absentee voting process),[24] and others made no attempt to preserve the privacy of voters they assisted.[25] Whereas an increasing number of nations now promise equality of opportunity for people with disabilities, very few, if any, come close to delivering it. This failure severely restricts the ability of some 500 million people around the world to contribute fully to the civil, political, economic, social, and cultural lives of their communities.

Legal mechanisms, both national and international, to protect and promote the rights of people with disabilities, are generally inadequate. Worldwide, people with disabilities continue to receive disparate treatment at the hands of the law. Of 189 UN Member States, only some 40 have any form of anti-discrimination law for persons with disabilities,[26] and in those that do, much work remains to be done to implement and enforce the provisions on the books.[27] Where national laws and policies have sought to address the concerns of people with disabilities, all too often the language and approaches adopted have served to further reinforce stereotypical perceptions of people with disabilities as passive, sick, dependent, and in need of medical cures and charity.

The human rights condition of people with disabilities has real application and relevance to all citizens, not only the international community, scholars, or those already familiar with international law and policy. The affirmation and implementation of human rights principles for

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[23] *Id.* at 31. In this particular instance, a portable voting booth was available, but it had been configured for demonstration purposes only, so that "George Washington" and "John Adams" were listed as the presidential candidates.

[24] *Id.* at 51.

[25] *Id.* For instance, at a Bloomington polling station, polling staff required that two staff (one from each party) be present in the voting booth of one disabled voter requiring assistance, and no effort was made to preserve the voter's privacy.

[26] DEGENER & QUINN, *supra* note 17, §4.6.

[27] Metts, *supra* note 1, at 29.

all minority groups form the foundation of a just society, both here in the United States and in countries around the world. In fact, these principles are vital to the peace and prosperity of every society. It has become increasingly apparent that human rights issues of concern to people with disabilities play a critical part in the quest to achieve international peace and security and the promotion of democracy. Enhancing the status of disenfranchised minorities, of which people with disabilities constitute a large group, will contribute to the realization of the three pillars of Secretary General Kofi Annan's vision for the UN in the next century, namely, (i) eradicating poverty; (ii) preventing deadly conflict; and (iii) promoting democracy.[28] These three concepts are also at the core of US foreign policy. Put simply, the eradication of poverty will not be achieved absent a concerted effort to reach *all* vulnerable groups; the prevention of deadly conflict cannot happen without the full participation of war-wounded citizens and people with disabilities; and the promotion of democracy will be incomplete without the full inclusion of all human beings with rights, irrespective of their minority status.

Unfortunately, interested governments and the collective voice of people with disabilities have had very limited success in placing disability rights onto the international human rights agenda. This contrasts with other specified groups, such as racial or ethnic minorities, women, children, and indigenous peoples, who have succeeded in so doing, thereby drawing attention and responses to human rights abuses specific to them at the national and international levels. Clearly, the absence of any international treaty specifically addressing the rights of persons with disabilities has contributed to the invisibility of disability issues and disability rights on the agenda of international institutions and programs. As a result of that absence, efforts to leverage resources and draw attention to the rights of people with disabilities have been largely ineffective.[29]

Despite their marginalized and disempowered status, people with disabilities and their grassroots organizations are engaging in the struggle for their inclusion in society and

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[28] Nobel lecture given by the 2001 Nobel Peace Prize Laureate, Kofi A. Annan, Oslo, December 10, 2001, available at <http://www.nobel.no/eng_lect_2001b.html>.

[29] Theresia Degener & Gerald Quinn, *A Survey of International, Comparative and Regional Law Reform*, DREDF CONFERENCE PAPER, 10, fn. 37, available at <http://www.dredf.org>.

participation in decision-making arenas. People with disabilities in both the developed and developing world are themselves advocating for equal access to employment, health care, transport, housing, education, and culture and are reporting long untold stories of violence and abuse. On the international level, the current effort within the United Nations to draft an international convention on the rights of people with disabilities has the potential to focus attention on the lives of people with disabilities across the globe. Moreover, that effort can reveal the scope of a widespread human rights crisis and the valuable contributions the disability community has to offer both the convention process and global society. The treaty development process and the resulting legal standards can bring to the forefront of international policy a long-neglected area of human rights practice.

B. Purpose of the Paper

The purpose of this paper is to analyze how the support and participation of American policy makers and organizations representing people with disabilities in the drafting of an international human rights treaty specifically addressing disability rights will serve disabled people and their allies around the globe. This paper considers the important role that the United States and American disability organizations have to play in advancing the human rights of people with disabilities through participation in any forthcoming international human rights treaty process. At the same time, issues of concern regarding the challenges associated with any international human rights treaty process are recognized and addressed. The paper concludes with some suggested next steps and recommendations for consideration as the effort within the United Nations to draft a treaty on the rights of people with disabilities gets underway.

III. Background

A. Disability Law in the United States

Enacted in 1990, the Americans with Disabilities Act (ADA) was the result of broad-based advocacy efforts by members of the disability community and supporting members of Congress. It constitutes the federalization of the legal rights of people with disabilities, which had previously been included (to the extent that they were addressed at all) in state legislation and limited federal legislation.[30] Whereas previous legislation tended to focus on institutions that received government funding, the ADA extended the legal coverage to private entities, thus greatly expanding the legal protection of people with disabilities, as well as opening up many more opportunities for them in such environments as the workplace. The ADA is particularly notable for its inclusion of certain innovative concepts, such as the principle of "reasonable accommodation," which requires an employer to accommodate a qualified employee, unless doing so would cause significant difficulty or expense.[31]

In his launching of the New Freedom Initiative in February 2001, President George W. Bush acknowledged his commitment to "tearing down the remaining barriers to equality that face Americans with disabilities today" and recognized that "significant challenges remain for Americans with disabilities in realizing the dream of equal access to full participation in American society" to create "a nation where no one is dismissed or forgotten."[32] Thus, despite the

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[30] *See, e.g.*, the Rehabilitation Act, 29 U.S.C. § 791 et. seq. (1973), particularly § 504.

[31] "Reasonable accommodation" is defined in the ADA as the following:

> (9) REASONABLE ACCOMMODATION.--The term "reasonable accommodation" may include-
> (A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and
>
> (B) job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities.

Americans with Disabilities Act, 42 U.S.C. § 12111(9) (1990).

[32] NEW FREEDOM INITIATIVE, FORWARD BY PRESIDENT GEORGE W. BUSH (February 2001).

successful passage of the ADA, its incorporation into the US legal system as well as public consciousness has not been without problems. The results of a 1998 study reveal that only 54 percent of American adults with disabilities have heard of the ADA. Notwithstanding the social and legal benefits achieved as a result of the work of disability advocates in the United States, the need to continue efforts to raise awareness and educate is tremendous.[33]

Even with the passage of this path-breaking legislation, lawsuits brought under the ADA have been difficult to win. Employers prevailed in 93 percent of cases reaching the trial court level from 1992 to1998 and 84 percent of the time on appeal.[34] According to the Equal Employment Opportunity Commission (EEOC), disability-based harassment ranks among the fourth most frequent cause for claims behind sexual harassment, racial harassment, and harassment claims based on national origin.[35] Thus, while the ADA has been a crucial catalyst for social change, much remains to be done, according to Richard Scotch:

> [I]n the first decade of implementation ADA appears to have fallen short of its optimistic goal to change fundamentally the lives of most Americans with disabilities. In the aggregate, people with disabilities are still as disproportionately underemployed as before ADA's enactment, and their incomes are still significantly below those of people without disabilities. While survey data implies that most Americans are supportive of ADA's goal of inclusion and non-discrimination, ample anecdotal evidence suggests that physical barriers, individual attitudes, and restrictive institutional processes continue to constrain most Americans with disabilities.[36]

In other words, there are active forms of discrimination, as well as "neutral barriers," that inhibit disabled people's enjoyment of their human rights.

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[33] DORIS ZAMES FLEISCHER & FREIDA ZAMES, THE DISABILITY RIGHTS MOVEMENT xvi (Temple University Press 2001).

[34] Reed Abelson, *Employers Increasingly Face Disability-Based Cases*, N.Y.T IMES, Nov. 20, 2001, at C.

[35] *Id.*

[36] RICHARD K. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY 178 (Temple University Press, 2d ed., 2001).

The process of developing, implementing, and monitoring an international convention on the human rights of people with disabilities will serve to engage a wide variety of actors in analyzing and identifying the shortcomings of national law models. Both the development of a treaty and its implementation provide opportunities for stakeholders to assess valuable domestic models of disability law and policy, including, but not limited to, the ADA. As a result of their national experience, people with disabilities and disability advocates in the United States have much to contribute to the international treaty-making process and can help their counterparts in other countries to achieve their national vision, which in many cases is inspired by the promise of the ADA. The failure of the American disability community to engage in this process will come at a heavy cost: not only will others miss the benefit of their experience, but also the community will be left out of a process that has great potential to support advocacy efforts related to the ADA. In sum, engagement in the process stands to support and invigorate US domestic initiatives that will strengthen ADA-focused advocacy. The American disability community ignores the international human rights process at its peril.

B. Human Rights for People with Disabilities and the International Human Rights System

i. The Emergence of International Human Rights Law

The Universal Declaration of Human Rights (UDHR), adopted by the United Nations General Assembly in 1948, signaled the emergence of modern international human rights law.[37] In its expression of general human rights principles in the area of civil, political, economic, social, and cultural rights, the UDHR emphasizes its applicability to all people, underscoring that "[a]ll human beings are born free and equal in dignity and rights,[38] ... [a]ll are equal before the law, and [all] are entitled without any discrimination to equal protection of the law."[39] Although

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[37] G.A. Res. 217A (III), U.N. Doc. A/810 at 71 (1948).

[38] Universal Declaration of Human Rights, Dec. 10, 1948, art. 1, G.A. Res. 217A (III), at 71, U.N. Doc A/810 (1948).

[39] *Id.*

the UDHR is a declaration and not an international treaty, it is now widely recognized as part of customary international law and therefore possesses legal force.

The adoption of the UDHR was followed by the drafting of two international treaties that, together with the UDHR, make up the International Bill of Human Rights and the core of modern international human rights law. In 1996, the UN General Assembly opened for signature the International Covenant on Civil and Political Rights (ICCPR)[40] and the International Covenant on Economic, Social and Cultural Rights (ICESCR).[41] These treaties, ratified as of February 2002 by 148 and 145 Member States respectively, legally oblige States Parties to implement their provisions subject to any qualifying reservations. While the International Bill of Rights provides protections applicable to all people, no explicit mention is made of discrimination on the grounds of disability in these instruments.[42] As Professor Theresia Degener has emphasized, where disability is addressed in the International Bill of Rights, "it is only in connection with social security and preventive health policy,"[43] and not as a comprehensive human rights issue.

Thus, all human beings, regardless of what physical, sensory, or mental abilities they may have, are entitled to the same human rights as a matter of international law, yet people with

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[40] G.A. Res. 2200A, 21 U.N. GAOR, Supp. No. 16, at 52, U.N. Doc. A/6316 (1966).

[41] G.A. Res. 2200A, 21 U.N. GAOR, Supp. No. 16, at 49, U.N. Doc. A/6316 (1966).

[42] The UDHR makes only one reference to disability. Article 25 provides that: "[E]veryone has the right to a standard of living adequate for the health and well-being of himself and his family, ... and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control." Specific mention of disability appears in some international human rights treaties, such as the following: Convention on the Rights of the Child, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), *entered into force* 2 Sept. 1990, Articles 2(1) and 23; African [Banjul] Charter on Human and Peoples' Rights, adopted June 27, 1981, *entered into force* Oct. 21 1986, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), Article 18(4); and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, O.A.S. Treaty Series No. 69 (1988), signed November 17, 1988, reprinted in Basic Documents Pertaining to Human Rights in the Inter-American System, OEA/Ser.L.V/II.82 doc.6 rev.1 at 67 (1992), Article 18. More recently, the Inter-American human rights system adopted the Inter-American Convention on the Elimination of All Forms of Discrimination Against People with Disabilities, although it is limited in scope and suffered from inadequate participation by the disability community. Inter-American Convention on the Elimination of All Forms of Discrimination Against People with Disabilities, 7 June 1999, A-65, AG/RES. 1608 (XXIX-0/99), available at <http://www.oas.org/juridico/english/ga-res99/eres1608.htm >.

[43] Theresia Degener, *Disabled Persons and Human Rights: The Legal Framework*, *in* HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS 94 (Theresia Degener & Yolan Koster-Dreese, eds., 1995).

disabilities have remained largely invisible in human rights law and practice and violations and egregious abuses against them all too often go unnoticed, unreported, and, consequently, unaddressed. Although the International Bill of Rights and other international human rights instruments proclaim that all human beings are born free and equal in dignity and rights, millions of people with disabilities face daily assaults on their freedoms and suffer indignities that violate their most basic human rights.

ii. Addressing the Human Rights of Specific Populations

Early developments in international human rights law served to bolster the concept that human rights standards and the violation of those rights by a State against its own nationals are indeed a matter of international concern, thereby discrediting claims to the contrary. It was soon discovered, however, that additional legal measures were required in order to address human rights abuses experienced throughout the world by individuals belonging to particular social, ethnic, religious, and other groups. Beginning in the mid-1960s, the United Nations began to recognize the vulnerability of certain populations to human rights abuses that were not addressed with any degree of specificity in existing international human rights law. Well-coordinated international campaigns led to the adoption of a number of specialized human rights instruments to address gaps in the law and establish permanent mechanisms for more effective monitoring of violations. These instruments include, among others, the UN Convention on the Elimination of All Forms of Racial Discrimination,[44] the UN Convention on the Elimination of All Forms of Discrimination Against Women,[45] the UN Convention on the Rights of the Child,[46] the International Labour Organization Convention Concerning Indigenous and Tribal Peoples in

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[44] 660 U.N.T.S. 195, *reprinted in* 5 I.L.M. 352 (1966).

[45] G.A. Res. 34/180, 34 U.N. GAOR, Supp. No. 46, U.N. Doc. A/34/46 at 193 (1979), *reprinted in* 19 I.L.M. 33 (1980).

[46] G.A. Res. 44/25, 44 U.N. GAOR, Supp. No. 49, U.N. Doc. A/44/49 at 167 (1989), *reprinted in* 28 I.L.M. 1448 (1989).

Independent Countries,[47] and the International Convention on the Protection of the Rights of All Migrant Workers.[48]

These treaties create legal protections that address in concrete terms the social, political, and cultural circumstances that impact the human rights conditions of these populations. Most significantly, they frequently provide for the establishment of permanent treaty-monitoring bodies composed of recognized experts in the field of human rights and endowed with the authority to scrutinize and promote compliance with treaty provisions. The process of drafting these focused conventions has served to raise awareness and build capacity among both governments and non-governmental organizations concerned with the human rights issues pertaining to these various populations. Once the treaties have entered into force, they provide a forum for the consideration of human rights issues insofar as they pertain to the treaty and serve as a focal point for the human rights initiatives of governments and non-governmental organizations, spurring developments in national laws and highlighting best and worst practices.

iii. International Human Rights Law for People with Disabilities

The evolution of international human rights law as it applies to people with disabilities has proceeded along an entirely separate and, unfortunately, less progressive course. During the 1970s, the Declaration on the Rights of Mentally Retarded Persons[49] and the Declaration on the Rights of Disabled Persons[50] were the first international human rights instruments to embody human rights principles relating specifically to people with disabilities. These were significant steps in terms of raising awareness about the human rights of people with disabilities. They came under heavy criticism by the disability community, however, for their expression of outmoded

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[47] I.L.O. 27 June 1989, Convention 169, I.L.O. Conventions 169, LXX11 I.L.O. Official Bull., Ser. A, No. 2 at 63 (1989), *entered into force* 5 Sept. 1991.

[48] G.A. Res. 45/158, *reprinted in* 30 I.L.M. 1517 (1991).

[49] Declaration on the Rights of Mentally Retarded Persons, G.A. Res. 2856 (XXVI), 26 U.N. GAOR Supp. (No. 29) at 93, U.N. Doc. A/8429 (1971).

[50] Declaration on the Rights of Disabled Persons, G.A. Res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975).

medical and charity models of disability that serve to reinforce paternalistic attitudes about people with disabilities. Thus, for example, the 1971 Declaration on the Rights of Mentally Retarded Persons was criticized for qualifying the scope of rights for people with intellectual disabilities both in providing that "the mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings"[51] and in terms of its goal for societies, which is to promote "their integration as far as possible in normal life."[52]

Although further progress was made in the development of international standards relating to disability, these efforts did not culminate in legally binding measures. These efforts included the United Nations Decade of Disabled Persons (1982-1993), during which the World Programme of Action Concerning Disabled Persons[53] and two new international human rights instruments pertaining to disability were adopted by the UN General Assembly. In 1993, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted as a blueprint for policy-making and provided a basis for technical and economic cooperation among States. The UN Standard Rules establish a monitoring mechanism through the appointment of a Special Rapporteur who reports to the Commission on Social Development.[54] The Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care (MI Principles) were adopted in 1991[55] and set forth principles that can serve as a common standard for the evaluation of the implementation of human rights practices in

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[51] Declaration on the Rights of Mentally Retarded Persons, *supra* note 49.

[52] *Id.*

[53] G.A. Res. 37/52 (1982). Published by the Division of Economic and Social Information and the Centre for Social Development and Humanitarian Affairs (Nov. 1983, DESI.S97).

[54] UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 85th Plenary Meeting, 20 Dec. 1993, ¶ 1, Part IV, A/Res/48/96. The Special Rapporteur is mandated to consult with a panel of experts and presents States with questions concerning their implementation of the Rules. The Special Rapporteur also provides advisory services and engages in constructive dialogue with governments and disability organizations regarding the implementation of the Rules.

[55] G.A. Res. 119, U.N. GAOR, 46th Sess., Supp. No. 49, Annex at 188-192, U.N. Doc. A/46/49 (1991).

national mental health systems.[56] These documents add content to existing human rights provisions housed in the general instruments. Nonetheless, the documents are not housed in a treaty, nor are they widely regarded as having attained the status of customary international law.[57] Most significantly, the UN Standard Rules and the MI Principles do not establish permanent bodies to monitor compliance with their provisions. Thus, in spite of the progress made, governments and non-governmental organizations are left without any permanent and adequately resourced human rights body devoted to monitoring human rights violations against people with disabilities and without effective means to promote further developments in both national and international law.

The prevailing opinion of professionals working in the fields of disability and international human rights law is that the current international human rights framework is, in the context of disability, deficient in two fundamental respects. First, without specific attention and language devoted to the most common practices leading to the violation of human rights for people with disabilities in any single international human rights treaty, many governments remain unaware of their legal obligations.[58] Consequently, the international human rights framework rarely is used to protect people with disabilities. Second, as a recent study demonstrates with persuasive force, the existing human rights treaty-monitoring bodies established by a variety of international human rights treaties only marginally address, if at all, the routine human rights

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[56] For more on the MI Principles, see Eric Rosenthal & Leonard S. Rubenstein, *International Human Rights Advocacy under the 'Principles for the Protection of Persons with Mental Illness,'* 16 INT'L J. L. & PSYCHIATRY 257 (1993).

[57] Customary international law is that law that "results from a general and consistent practice of states followed by them from a sense of legal obligation." Restatement of the Law (Third) § 102(2). *See also* Article 38(1), I.C.J. Statute, which provides that the International Court of Justice "shall apply ... international custom, as evidence of a general practice accepted as law." In other words, a practice can become binding international law if enough States participate in the practice and do so because they feel they are legally obliged to uphold the practice. Although not every State needs to uphold the practice for it to become law, "once a practice has acquired the status of law, it is obligatory for all states that have not objected to it." THOMAS BUERGENTHAL & HAROLD G. MAIER, PUBLIC INTERNATIONAL LAW 24 (West 2nd ed., 1990).

[58] Rosenthal, *supra* note 18, at 70-71.

violations to which people with disabilities are subjected.[59] A notable lack of jurisprudence on the rights of people with disabilities exists as a matter of international human rights law.[60]

An additional factor that reinforces the failure of existing human rights mechanisms to address the human rights of people with disabilities is the lack of capacity among international human rights organizations and the disability community to use the human rights machinery in advocacy for disability rights. Organizations devoted to the protection of human rights have generally failed to focus on abuses against people with disabilities or to develop the capacity to investigate and report on disability-based human rights violations. In some instances, well-meaning humanitarian assistance organizations have unwittingly perpetuated human rights abuses against people with disabilities through "charity" programs that serve to perpetuate discriminatory programs that ultimately disempower people with disabilities.[61]

Against this background, new proposals for the adoption of an international treaty addressing the rights of people with disabilities are currently underway. The effort is not to secure special privileges or to reinforce a segregated treatment of people with disabilities through the establishment of a separate treaty. Rather, the aim is to secure unequivocal protection for the fundamental human rights and freedoms of people with disabilities and to acknowledge their legitimate membership in the international human rights system.

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[59] *See* DEGENER & QUINN, *supra* note 17.

[60] General Comment No. 5 issued by the Committee on Economic, Social and Cultural Rights is a notable exception to the general rule that treaty-monitoring bodies have not given adequate attention to how disability relates to the specific protections provided in the relevant treaties. General Comment No. 5 does provide interpretative guidelines of the application of economic, social and cultural rights to people with disabilities. ICESCR Committee, General Comment 5, *Persons with Disabilities*, Eleventh Session, U.N. Doc. E/1995/22 (1994). For an excellent analysis of General Comment No. 5 and how disability organizations can use this work and the machinery of the Committee, see DEGENER & QUINN, *supra* note 17, §5.5.

[61] Mental Disability Rights International (MDRI) reports that in numerous countries it has observed how some of the most widely respected humanitarian relief programs, including programs funded by the US government, support and reinforce segregated models of social services for people with disabilities that would be contrary to public policy or civil rights law in the United States. Frequently, foreign assistance funding is used to rebuild old buildings and provide shelter, social support, and medical care exclusively within institutions—ignoring the efforts of disability activists who are desperately seeking funding for programs that would support people in the community or keep them out of institutions. Eric Rosenthal, et. al., *Implementing the Right to Community Integration for Children with Disabilities in Russia: A Human Rights Framework for International Action*, 4 HEALTH & HUMAN RIGHTS 83, 89 (1999).

iv. Proposals for an International Human Rights Treaty for People with Disabilities

Support for an international human rights treaty for people with disabilities is evidenced by the numerous calls for such an instrument by actors within the global disability community. During March 2000, participants[62] at the World NGO Summit on Disability convened in Beijing to discuss a possible treaty delineating the human rights of people with disabilities. The declaration that issued from that meeting urged "all heads of state and government, public administrators, local authorities, members of the United Nations system, people with disabilities, civic organizations that participate in the development process, and socially responsible private sector organizations, to immediately initiate the process for an international convention."[63]

In calling for such a treaty, the participants highlighted the following as areas of specific concern to be addressed by the treaty:

(a) Improvement of the overall quality of life of people with diverse disabilities and their upliftment from deprivation, hardship, and poverty.

(b) Education, training, remunerative work, and participation in decision-making processes at all levels.

(c) Elimination of discriminatory attitudes and practices, as well as information, legal, and infrastructural barriers.

(d) Increased allocations of resources to ensure the equal participation of people with disabilities.[64]

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[62] Participants included Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, and the World Federation of the Deaf, as well as various national non-governmental organizations.

[63] Beijing Declaration on the Rights of People with Disabilities in the New Century, adopted on 12 March 2000 at the World NGO Summit on Disability, ¶ 7, available at <http://www.unescap.org/decade/beijdeclarfin.htm>. It should be noted that other disability NGOs have issued similar declarations, including calls for an international human rights treaty for people with disabilities. For instance, Rehabilitation International similarly called for a "UN Convention on the Rights of People with Disabilities" in its Charter for the Third Millenium, issued in September of 1999 and available at <http://www.rehab-international.org/charter.html>.

[64] Beijing Declaration *supra* note 63, ¶ 8.

The momentum for a treaty was continued when, on November 28, 2001, the UN General Assembly adopted by consensus a resolution initiated by Mexico calling for the establishment of an Ad Hoc Committee mandated to elaborate "a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the field of social development, human rights and non-discrimination."[65] This step builds on the efforts of other countries in recent years, most notably Ireland, to develop support within the United Nations for a treaty on the rights of people with disabilities.[66]

The ensuing process presents both challenges and opportunities that can lead to the adoption of a comprehensive convention on the rights of people with disabilities in a fully participatory process that reflects latest developments in international law and policy and establishes effective machinery for monitoring compliance with human rights obligations. The failure of the American disability community to engage in the development of international human rights law concerning people with disabilities will jeopardize the success of the current treaty-initiative and compromise future implementation efforts. Members of the global disability community have much to gain from the active participation of their American counterparts and, in turn, Americans stand to benefit from lending their voice to the convention dialogue.

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[65] *Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities*, *supra* note 1.

[66] *See Summary Report of a Conference on the Theme: "Towards a United Nations Convention on the Human Rights of Persons with Disabilities,"* organized by the Department of Foreign Affairs of Ireland, the National Disability Authority and the Irish Human Rights Commission, Royal Hospital Kilmainham, Dublin, Ireland, February 26, 2002, summarizing, among other things, the successive efforts by Ireland to support developing an international human rights treaty for people with disabilities.

IV. Addressing the Human Rights of People with Disabilities

A. A Paradigm Shift: Transforming "Needs" into Rights

Human rights are not the exclusive property of any one group to be guarded and shared with only a privileged few. Human dignity belongs to all and is to be shared by all equally. As different groups have laid claim to their human rights over time, it is not the concept that has expanded, but rather, its applicability. The specific experience of marginalized groups must be incorporated into contemporary human rights interpretations of law for it to be empowering for all. People with disabilities, under this transformative view, will become more visible by articulating their human rights and communicating their lived experiences, so that existing human rights ideas and practices will fully take into account their lives. This entails a shift in thinking for people with disabilities from being passive recipients of charity to active claimants of their human rights.

i. Traditional vs. Contemporary Models of Disability

Traditional models of disability tend to start with the basic premise that the individual experiencing disability is the sole locus of any problems encountered by that person.[67] Thus, the medical and personal tragedy models of disability have long been the lens through which the majority has viewed people with disabilities. These models have tended to reinforce notions that people with disabilities are "broken" in some way, victims of some tragic circumstance, and need medical or rehabilitation experts to repair or overcome their disability so that they may participate fully in society. Simi Linton observes the following:

> [T]he medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to *disability*, colludes to keep the issue within the purview of the medical establishment, to keep

[67] For more on traditional models of disability, see Gareth Williams, *Theorizing Disability*, *in* HANDBOOK OF DISABILITY STUDIES 123 (Gary L. Albrecht, Katherine D. Seelman & Michael Bury eds., Sage Publications 2001).

it a personal matter and "treat" the condition and the person with the condition rather than "treating" the social processes and policies that constrict disabled people's lives.[68]

These models ignore the fact that the problems reside not in the individual, but in the "social, attitudinal, architectural, medical, economic, and political environment"[69] in which he or she lives. Furthermore, such models do not adequately define the important and appropriate role of the medical community, which is to promote human health for all people and to provide rehabilitation and support services in the best interests—and with the participation and informed consent—of the individual.

Largely because of activism of people with disabilities themselves, society has increasingly realized that disability is not an unusual or tragic situation that happens to a pitiable few. Scholarship in the field of disability studies has further supported the paradigm shift away from the medical model of disability wherein disabled people are sick and in need of a cure. Disability, under the new model, is seen as a social construction according to which *society, not* the person with a disability, requires adaptation.[70] The push for a cultural shift in thinking about disability, promoted by American consumer-based disability organizations as well as international disability organizations, has led to the documentation of interesting examples of societal inclusion or adaptation in response to disability. Thus, in Nora Groce's leading study, *Everyone Here Spoke Sign Language*,[71] the community in Martha's Vineyard, Massachusetts, learned sign language to communicate with deaf members, thereby creating adaptation and

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[68] SIMI LINTON, CLAIMING DISABILITY: KNOWLEDGE AND IDENTITY 11 (New York University Press 1998).

[69] Irving K. Zola, *Toward the Necessary Universalizing of a Disability Policy*, 67 MILBANK Q. 401, 406 (1989).

[70] For some of the leading work in the field of disability studies reflecting the social model of disability, see especially, MICHAEL OLIVER, THE POLITICS OF DISABLEMENT (Macmillan and St. Martin's Press 1990); LINTON, *supra* note 68; KENNY FRIES, ED., STARING BACK: THE DISABILITY EXPERIENCE FROM THE INSIDE OUT (Plume 1997); BENEDICTE INGSTAD, & SUSAN REYNOLDS WHYTE, EDS., DISABILITY AND CULTURE (Uni. Calif. 1995); VICTOR FINKELSTEIN, ATTITUDES AND DISABLED PEOPLE (1980).

[71] NORA GROCE, EVERYONE HERE SPOKE SIGN LANGUAGE (Harvard Uni. Press 1985).

accommodation. For indigenous communities, such as the Punan Bah of Sarawak and the Maasai of Kenya, people with disabilities are regarded as full participants in their societies and enjoy acceptance, as opposed to stigma and marginalization.[72]

The social model of disability captures the insight that full participation in society for people with disabilities will be achieved not by "fixing" people, but by breaking down the barriers that prevent realization of equal opportunity, full participation, and respect for difference. Under this view, empowerment requires the undoing of negative social constructions in such a way that people with disabilities see themselves as having the capacity and the right to participate fully in society and influence decision-making. In turn, others in society will likewise regard them as so endowed. Reframing disability in terms of social processes under the social model requires a broadened understanding of the sources of challenges faced by people with disabilities and a more balanced perception of how medicine, rehabilitation, and general health care fit into the equation, a perspective that many physicians and other health service providers do indeed understand. This reframing requires close scrutiny of all actors and processes, leading to a complete reorientation of the interaction between people with disabilities and society.

The insights provided by the social model of disability are now being applied to practical issues facing disabled people in terms of public policy, law, and community inclusion. As the UN Standard Rules have embraced the social model of disability, so too should an international convention on the rights of people with disabilities. A human rights framework that embraces a social model of disability has a greater capacity to identify and resolve those fundamental aspects of society that continue to oppress and exclude.[73]

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[72] Ida Nicolaisen, *Persons and Nonpersons: Disability and Personhood among the Punan Bah of Central Borneo*, 38; and Aud Talle, *A Child is a Child: Disability and Equality among the Kenya Maasai*, 56 *in* DISABILITY AND CULTURE (Benedicte Ingstad & Susan Reynolds White, eds., 1995).

[73] This notion is perhaps captured most succinctly by Bickenbach, who states the following:

> Disability advocates were thus able to argue that disability law and policy should not be a matter of charity, professional need, compensation, or economic necessity but instead must be grounded in human rights. The social model of disability plays a vital role in making the human rights approach plausible. On the social model, a person's inability to perform certain actions or to participate fully in social roles such as parent, student, or employee is, in part, a consequence of social attitudes and policies that create barriers. It makes little sense to say that one has a right, of any sort, not to have functional impairments because many impairments are outcomes of aging and other natural process that are unavoidable. It does makes [sic] sense to insist that one has a basic human right to be treated

ii. Rights-Based Approaches to Disability

The American civil rights movement involved a claiming of basic human rights that should be accorded to all people—the right to a decent education; the right to vote; the right to due process; the right to participate in the life of the community, whether through eating at a restaurant or attending a movie theater, without the threat of violence or harassment. The movement was not seeking "special rights," only basic rights grounded in the concepts of equality, non-discrimination, and human dignity.

The disability movement, both within the United States and internationally, is grounded in the same fundamental concepts and asks not for "special rights," but instead moves to embrace rights already enjoyed and to a large extent secured by non-disabled people. It emphasizes that "[w]e are all targets for inequitable and unjust treatment—disabled people often to a greater degree than others. Still, the struggle for people with disabilities is of the same nature as for all those who do not have the access to social goods that is their due."[74] The current call for attention to the human rights of people with disabilities is a natural continuation of the civil rights tradition and has emerged to challenge existing notions of human rights that have frequently trivialized and ignored the lives of people with disabilities.

A human rights approach has the power to transform the needs of people with disabilities into rights they can claim. Grounded in basic concepts of justice and human dignity, human rights enable people to reconceive their basic needs as a matter of rights to claim, rather than charity to receive. Furthermore, rights-based concepts stand to inform our thinking beyond strictly legal applications. As an example, in the development context, Peter Coleridge has emphasized how traditional models of development have often characterized people living in poverty as passive victims and recipients of aid and charity. A rights-based awareness of

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as an equal when one adds that social institutions and attitudes are responsible for creating disabling barriers that limit a person's participation in life activities. The social model and the human rights approach, in short, are mutually reinforcing.

Jerome E. Bickenbach, *Disability Human Rights, Law and Policy, in* HANDBOOK OF DISABILITY STUDIES 565, 567 (Albrecht et al., eds., Sage Publications 2001).

[74] HANDBOOK OF DISABILITY STUDIES 511 (Albrecht et al. eds., Sage Publications 2001).

disability, by contrast, compels significant shifts in thinking about disability and development.[75] In reorienting the focus from needs to rights, people with disabilities may be recognized as active rights-bearing individuals who are participants in their own development and who should be consulted accordingly in development decision-making.[76]

The adoption of a human rights–based approach has already led to tangible results for many other disenfranchised groups. The American civil rights movement, the South African anti-apartheid movement, and the international women's rights movement have all framed their claims in rights-based language, securing significant success in national legal reform initiatives.[77] During the last decade of apartheid in South Africa for example, human rights organizations initiated a human rights–based public education program in order to encourage the development of new legal strategies to challenge existing apartheid laws. Training in international human rights law was implemented for judges and lawyers. This training led to the invocation of international human rights treaty standards in the national legal system.[78] Ultimately, both activists and legal scholars sought to challenge the apartheid legal order on the basis that it violated international human rights treaty standards. This new culture of human rights led to the

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[75] For a comprehensive study that advocates a participatory approach to disability and development and is informed by a social model of disability see PETER COLERIDGE, DISABILITY, LIBERATION AND DEVELOPMENT (Oxfam 1993).

[76] The legal connotations of the social model of disability are straightforward and have been well expressed by Leandro Despouy:

> In a word, persons with disabilities, as persons like ourselves, have the right to live with us and as we do. From the legal point of view, there are three dimensions to this statement: (a) the recognition that persons with disabilities have specific rights; (b) respect for these and all their rights; and (c) the obligation to do what is necessary to enable persons with disabilities to enjoy the effective exercise of all their human rights on an equal footing with others.

Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Human Rights and Disabled Persons* ¶ 7 (1993).

[77] For a particularly good account of how the women's human rights movement succeeded in focusing attention on violence against women through a human rights approach, see MARGARET E. KECK & KATHRYN SIKKINK, ACTIVISTS BEYOND BORDERS 165-198 (Cornell University Press 1998).

[78] One regular participant, a sitting judge, invoked both the International Covenant on Civil and Political Rights and the European Convention on Civil and Political Rights, to find in support of an indigent person who had been sentenced to a long prison term without the assistance of counsel. R. Keightley, *International Human Rights Norms in a New South Africa*, SOUTH AFRICAN J. ON HUM. RTS. 171 (1992). The case in question was S. v. Khanyile, 1988 (3) SA 795 (N) at p. 801.

incorporation of international human rights norms into legislation, the Interim Constitution of 1993, and the 1996 Constitution. Thus, the use of human rights norms in South Africa culminated in the comprehensive incorporation of international human rights standards into domestic law and policy.

The framework of human rights is not only useful in efforts to lobby for legislative and policy changes but also provides an important tool for grassroots groups to organize around disability issues. Fundamental human rights principles accorded to each and every person provide disabled people with a vocabulary for describing violations of those rights as well as for describing impediments to the full realization of those rights. By framing their concerns in human rights terms, disability advocates gain access to important decision-makers within the international human rights system, as well as to national and local officials. Thus, an international convention on the rights of people with disabilities would help give the global disability community a tool with which to recognize and advocate for their rights and would press for consistency in law and policies both locally and nationally. A major challenge for governments initiating the call for an international treaty on the rights of people with disabilities will be to secure the active participation of people with disabilities in all stages of treaty development and implementation. That requires, among other things, adequate resources for international and regional meetings and careful attention to a range of accessibility issues in connection to such gatherings.

B. Universality and International Human Rights Law

International human rights law demands respect for the full dignity of every human being. Part of the strength of an international treaty on the rights of people with disabilities will be derived from its universality. International standards make unequivocal the fact that the human rights of people with disabilities are not culturally bound and are in fact intrinsic to all nations (though culture is not irrelevant in the *practice* of human rights). The significance of this point should not be underestimated in an international environment in which law reform initiatives regarded as linked exclusively with American interests are viewed with distrust or even outright hostility. To be sure, future attempts to generate law reform, whether in the constitutional, fraud

and corruption, criminal procedure, administrative law, or human rights spheres, need to be ever mindful of this and should therefore seek to work change through international channels. Moreover, international human rights treaties offer an appropriate vehicle for the wide dissemination and translation of international standards into local languages and are therefore of great practical significance to use as tools for national law and policy change.

The adoption of a treaty has much to commend it in terms of crafting a durable strategy for protecting the human rights of people with disabilities. The articulation of human rights principles for people with disabilities in a universally applicable treaty fully complements Irving Zola's persuasive call for the "universalization" of disability policy. Zola argued for "policies that recognize that the entire population is 'at risk' for the concomitants of chronic illness and disability,"[79] highlighting that "[t]he issue of disability for individuals ... is not whether but when, not so much which one, but how many and in what combination."[80] In other words, the notion of universalism as it applies to disability policy calls for the broadest possible approach to inclusion and equality of opportunity, such that disability policies are understood to benefit *all* human beings across the vast range of human variation. This approach supports and is supported by the theory of universal design, which promotes changes in the built environment for the benefit of all.[81] An international human rights treaty, both in its development and application, has real potential to embody the goals of a universal disability policy.

In sum, the current initiative to draft an international convention on the rights of people with disabilities presents the opportunity to convey within the framework of international law that a core group of disability rights transcend any particular culture and society and are therefore of universal importance and concern. At the same time, a treaty provides the appropriate

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[79] Zola, *supra* note 69, at 405.

[80] Irving K. Zola, *Disability Statistics: What We Count and What it Tells Us*, 4 J. OF DISABILITY POL. STUD. 9, 18 (1993).

[81] For discussions of the theory of universal design, see Ronald L. Mace, Graeme J. Hardie & Jaine P. Place, *Accessible Environments: Toward Universal Design, in* DESIGN INTERVENTION: TOWARD A MORE HUMAN ARCHITECTURE 155-75 (W.E. Preiser et al., eds., Van Nostrand Reinhold 1991); F. S. STORY, J. L. MUELLER & R. L. MACE , THE UNIVERSAL DESIGN FILE: DESIGNING FOR PEOPLE OF ALL AGES AND ABILITIES (North Carolina State University 1998); Metts, *supra* note 1, at 38-40.

framework for incorporating principles of American disability law that have yet to find a secure place in the international legal system. Thus, although the principle of reasonable accommodation has been reflected in a General Comment of the International Covenant on Civil and Political Rights, it is not a principle that is explicitly referenced in any of the main international human rights documents.[82] Little guidance exists in international law on the range of issues relating to accessibility that have a significant bearing on the enjoyment of so many fundamental human rights and freedoms. An international human rights treaty would be in keeping with legal and policy approaches that recognize the need to add specific content to well-established human rights principles that do not elaborate on their application to people with disabilities.

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[82] Eric Rosenthal & Clarence Sundram, *The Role of International Human Rights in Domestic Mental Health Legislation*, WHO REPORT [to be released in Spring 2002].

V. An International Convention on the Rights of People with Disabilities

A. Transformative Participation in an International Human Rights Treaty-Making Process

i. Raising Awareness about the Human Rights Condition of People with Disabilities

Whereas the provisions of an international human rights treaty for people with disabilities will serve to articulate specific rights and provide machinery for monitoring compliance with obligations, the transformative nature of the treaty-making process itself can generate an array of tangible benefits. These benefits include (i) raising the general public's awareness about the human rights of people with disabilities; (ii) highlighting abuses of those rights; (iii) further developing the knowledge-base of governmental and non-governmental participants; (iv) providing the impetus for extensive programmatic developments; (v) offering capacity-building opportunities for disability groups as a result of increased global focus on their issues; and (vi) providing data collection.[83]

The regional preparatory meetings and conferences typically associated with the treaty drafting process provide valuable opportunities for raising awareness of relevant issues among a

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[83] At this point, it may be useful to briefly describe the components of the treaty-making process. In essence, it involves the meeting of governments with a view to producing a legally binding document. The drafting of a human rights treaty under the auspices of the United Nations typically begins with a preparatory phase of regional meetings, which provides non-governmental organizations (NGOs) with a valuable opportunity to provide their input through either formal or informal channels. The preparatory phase is followed by a "conference of states parties," during which time the text of the treaty is usually finalized. NGOs may typically participate in both preparatory meetings and the treaty conference either as members of government delegations or as non-voting observers, in accordance with applicable rules of procedure. Those governments who wish to be bound by the terms of the treaty usually sign and then ratify the document within a particular deadline. Those countries that join after the deadline do so through a process known as "accession," which serves the same purpose as signature and ratification. Some treaties permit countries to make "reservations," "declarations," and "understandings," which will allow a country to exclude, modify, or clarify the legal effect of certain treaty provisions.

variety of actors.[84] Such fora serve to legitimize human rights issues and bring together unprecedented numbers of advocates, providing unique opportunities for information sharing, discussion of common concerns, and building relationships. The participation of disability organizations in the development of an international treaty on the human rights of people with disabilities will ensure their contribution to building the global knowledge base.[85] The process will provide numerous avenues for NGOs to provide information about the nature and scope of human rights violations against people with disabilities, as well as to develop strategies for addressing these violations. NGOs have devised increasingly sophisticated and creative methods to use the preparatory and conference phases of the treaty-making process to further their goals. For instance, Disabled Peoples' International (DPI) Women's Programme initiated a campaign to voice their concerns regarding the increasing use of eugenic health policies and practices, such as forced abortion and sterilization, as a part of their participation in the Beijing process. A common strategy has also been the use of peoples' hearings and tribunals in which survivors of human rights abuses bear witness to their experiences.[86] Additionally, conferences have provided the opportunity for NGOs to engage in media workshops in which participants learn to monitor the

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[84] World conferences have been extremely useful for raising awareness about women's rights issues. *See, e.g.*, Julie Mertus & Pamela Goldberg, *A Perspective on Women and International Human Rights After the Vienna Declaration: The Inside/Outside Construct*, 26 N.Y.U. J. INT 'L L. & POL. 201 (1994). Examples of awareness-raising initiatives can be found in International Women's Tribune Centre, *Claiming Our Rights*, 51 THE TRIBUNE—A WOMEN AND DEVELOPMENT Q. (March 1994); International Women's Tribune Centre, *Get Ready! Connecting Beijing to Action at Home*, 52 THE TRIBUNE—A WOMEN AND DEVELOPMENT Q. (November 1994); International Women's Tribune Centre, *Get Set! NGO's Worldwide Prepare for Beijing*, 53 THE TRIBUNE—A WOMEN AND DEVELOPMENT Q. (July 1995).

[85] For a detailed account of the process of drafting the UN Convention on the Rights of the Child and the central role NGOs played in that process and now play in implementing the treaty, see Cynthia Price Cohen, *Drafting of the United Nations Convention on the Rights of the Child: Challenges and Achievements*, *in* UNDERSTANDING CHILDREN'S RIGHTS: COLLECTED PAPERS PRESENTED AT THE FIRST INTERNATIONAL INTERDISCIPLINARY COURSE ON CHILDREN'S RIGHTS (Eugeen Verhellen ed., University of Ghent, 1996).

[86] Witness, for example, the use of these methods at the 2001 World Conference Against Racism where members of racial minorities, including groups of Afro-Latinos, Dalits, and Roma, who had never before had the opportunity to share their stories of abuse and discrimination were able to participate in public hearings in an international forum. Gay McDougal, International Human Rights Law Group, Panel Presentation, "World Conference Against Racism," 96th American Society of International Law Annual Meeting, Thursday, March 12, 2001.

media and acquire media literacy skills.[87] These and other activities serve as a potent catalyst for human rights advocacy at all levels and will provide unique and important occasions for disability organizations to raise awareness and build skills.

Through participation in the treaty-making process, engaged governments can be prompted to focus on disability issues, and the knowledge gained can be translated into action through law and policy reform, public-education programs, and other attitude-changing initiatives. A treaty process provides governments the chance to take stock and evaluate existing legal and policy approaches at the domestic level in addition to sharing with foreign counterparts their own domestic experience.

Similarly, intergovernmental organizations can be prompted by an international campaign to take action to gather and disseminate information on topics related to disability and to change their programming to better address disability issues. It is now standard within international organizations to provide some kind of institutional response in support of major international conferences on human rights issues. Thus, the World Bank expressed its institutional support for the 2001 World Conference against Racism by holding an event in the atrium of its main complex at headquarters, thereby contributing to the awareness-raising efforts about the impact of racism on poverty. Private actors, such as the media, can also be motivated in following the treaty-making process to portray the issues and affected populations in a manner that does not serve to buttress and reinforce inaccurate stereotypes. That is a matter of fundamental concern given the recognition by the disability community that the portrayal of people with disabilities in popular culture and the media supports myths of dependency and inability.[88]

An effective international human rights treaty will capitalize on the transformative

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[87] Further activities include photographic and video exhibitions, art and drama programs, campaigns and petitions, poster displays, electronic networking, and human rights education and community-organizing workshops, all of which serve to highlight the work of NGOs and create opportunities for sharing information and strategies. International Women's Tribune Centre, *Get Ready! Connecting Beijing to Action at Home*, 52 THE TRIBUNE—A WOMEN AND DEVELOPMENT Q. 34-41 (November 1994); International Women's Tribune Centre, *Get Set! NGO's Worldwide Prepare for Beijing*, 53 THE TRIBUNE—A WOMEN AND DEVELOPMENT Q. 8-25 (July 1995).

[88] For a discussion of the portrayal of people with disabilities in popular culture and the media, see JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT32-39 (Random House, 1994); OLIVER, *supra* note 70.

benefits of the treaty-making process by implementing provisions that seek to maintain the momentum developed during that preparatory period. Past experience shows that treaties are an impetus for the development of human rights education materials.[89] Education and awareness generated about disability and the human rights of people with disabilities will not and should not end with the adoption of an international treaty and may indeed be addressed in the text of an international convention on the human rights of people with disabilities. Thus, in international treaties relating to the protection of workers, education and training in relevant issue areas are addressed in treaty provisions.[90] For example, the International Convention on the Elimination of All Forms of Racial Discrimination, a treaty to which the United States is a party, provides in Article 7 that States Parties "undertake to adopt immediate and effective measures, particularly in the fields of teaching, education, culture and information, with a view to combating prejudices which lead to racial discrimination and to promoting understanding, tolerance and friendship among nations and racial or ethnic groups, as well as to propagating the purposes and principles of the Charter of the United Nations, the Universal Declaration of Human Rights, the United Nations Declaration on the Elimination of All Forms of Racial Discrimination, and this Convention."[91] Similarly, many international environmental agreements now include provisions

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[89] Examples of human rights materials that have grown out of specific human rights treaties include: SAVE THE CHILDREN, CHILDREN'S RIGHTS: EQUAL RIGHTS? (2000); JULIE MERTUS, NANCY FLOWERS & MALLIKA DUTT, LOCAL ACTION GLOBAL CHANGE: LEARNING ABOUT THE HUMAN RIGHTS OF WOMEN AND GIRLS (UNIFEM, 1999); WOMEN LAW AND DEVELOPMENT INTERNATIONAL & HUMAN RIGHTS WATCH, WOMEN'S HUMAN RIGHTS STEP-BY-STEP (1997). While there are certainly some materials which highlight the human rights of people with disabilities, the scope of these materials has yet to achieve the same coverage as that of materials relating to other areas of human rights, such as those referenced above. Existing materials include: NORWEGIAN ASSOCIATION FOR DEVELOPMENTAL DISABILITY, MY RIGHTS: A BOOKLET TO ACCOMPANY VIDEO ON THE EQUAL HUMAN RIGHTS OF PEOPLE WITH MENTAL DISABILITIES; SAVE THE CHILDREN SWEDEN, DISABLED CHILDRENS RIGHTS—A PRACTICAL GUIDE (Save the Children, 2001); RODRIGO JIMÉNEZ SANDOVAL, ELIMINADO BARRERAS CONSTRUYENDO OPORTUNIDADES (Disabled Peoples' International, Justicia & Genero, & ILANUD, 1997); RODRIGO JIMÉNEZ SANDOVAL, CONOCIENDO DERECHOS Y CUMPLIENDO CON OBLIGATIONS (Disabled Peoples' International & ILANUD, 1999).

[90] *See, e.g.*, Asbestos Convention, I.L.O. 4 June 1986, Convention 162, I.L.O. Conventions 162, *entered into force* 16 June 1989, Article 22 (regarding education on the hazards of asbestos and methods of prevention and control); Safety and Health in Construction Convention, I.L.O. 1 June 1988, Convention 167, I.L.O. Conventions 167, *entered into force* 11 Jan. 1991, Article 33 (regarding education and training of workers in workplace hazards and methods of prevention).

[91] International Convention on the Elimination of All Forms of Racial Discrimination, G.A. Res. 2106 A(XX).

requiring States to improve public education and awareness on environmental matters and to give due publicity to matters of environmental importance.[92] These are important precedents for those engaged in the drafting process for a treaty on the rights of people with disabilities given that education and awareness are core components of all disability advocacy.

Two main obstacles to raising awareness about the human rights condition of people with disabilities relates to the insufficient credible documentation on human rights abuses against people with disabilities and the dearth of statistical information and indicators about disability. The establishment of a strong treaty-monitoring body within the framework of a convention on the rights of people with disabilities mandated to review and act on State reports, individual and group complaints, and reports submitted by non-governmental organizations. A permanent, sufficiently resourced treaty-monitoring body will mark a new beginning in an important new area of human rights practice that requires strengthening.

In addition, a treaty provides the opportunity to set up a structure for more cost-effective and relevant data gathering and assessment of disability, which remains scarce, random, and inadequate for systematic analysis of disability issues. There is widespread consensus for the need to improve disability-related data collection and its use.[93] The formulation of guidelines on data collection and assessment, or the establishment of a treaty-based body with related functions, can help strengthen the capacity of national and international efforts to collect and use data relating to disability in their decision-making and further facilitate the gathering of information. Such a function, though not familiar to human rights treaties, is well developed in other international law contexts.

Perhaps the best illustration in this context is provided in the international environmental law context, where reliable data collection and its use are critical to the success of environmental protection efforts. International environmental agreements have often established standing

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[92] *See, e.g.*, Montreal Protocol on Substances that Deplete the Ozone Layer, 16 Sept. 1987, *entered into force* 1 Jan. 1989, *reprinted in* U.K.T.S. 19 (1990); Cm. 977; 26 I.L.M. (1987) 1550; 17 E.P.L. (1987) 256, Article 9(2); Basel Convention, 22 Mar. 1989, *entered into force* 5 May 1992, *reprinted in* 28 I.L.M. 657, Article 10(4); United Nations Framework Convention on Climate Change, 9 May 1992, *entered into force* 24 March 1994, *reprinted* in 31 I.L.M. 849 (1992), Article 4(1)(i).

[93] Zola, *supra* note 80, at 9; Nora Ellen Groce, Mary Chamie, & Angela Me, *Measuring the Quality of Life: Rethinking the World Bank's Disability Adjusted Life Years*, 3 DISABILITY WORLD (June-July 2000).

committees or scientific councils with the competence to provide recommendations on technical matters, necessary research, coordination of research, and evaluation of results and other specialized matters bearing on the implementation of the treaty.[94] In addition, in some human rights contexts, the use of statistical indicators has served to inform governments and has served, in addition, to empower grassroots organizations to hold governments and other powerful actors accountable for the effects of their policies on human rights.[95] Finally, given the tendency of statistical assessment in some instances to reinforce medical models of disability, the establishment of a data collection mechanism tied to a treaty that provides expressly for the participation of people with disabilities in data collection and assessment is compelling.

ii. Building Coalitions of People with Disabilities and their Allies Across Transnational Civil Society and Capacity Building

International conferences where treaties or non-binding documents are adopted provide critical opportunities for networking and coalition-building among NGOs and other actors, quite apart from seeking to raise awareness and influence formal proceedings. An international treaty process provides opportunities to forge coalitions between disability organizations, across disability lines, and among non-disability-specific human rights and other governmental and non-governmental organizations.[96] The process whereby the passage of the ADA was made possible serves as a salient example of how frequently disparate and disconnected groups may be brought

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[94] *See, e.g.*, Article 9, United Nations Framework Convention on Climate Change, 9 May 1992, *entered into force* 24 March 1994, *reprinted* in 31 I.L.M. 849 (1992); Article XV, Convention on the Conservation of Antarctic Marine Living Resources, 20 May 1980, *entered into force* 7 April 1982, 19 I.L.M. 849 (1980); Article 14, Convention on the Conservation of European Wildlife and Natural Habitats, 19 September 1979, *entered into force* 1 June 1982, U.K.T.S. 56 (1982); Article VIII, Convention on the Conservation of Migratory Species of Wild Animals, 23 June 1979, *entered into force* 1 November 1983, *reprinted in* 19 I.L.M. 15 (1980).

[95] Sarah Zaidi, *Using Indicators to Guide Advocates*, 2 HUM. RTS. DIALOGUE 17 (Spring/Summer 2001).

[96] In the context of the Landmine Ban Treaty, the "success of the landmine campaign can be attributed in broad measure to the strength and cohesiveness of the [International Campaign to Ban Landmines] ICBL, the [International Committee of the Red Cross] ICRC, the core group of States, the UN, and to the strategic coordination of their respective efforts." Don Hubert, *The Landmine Ban: A Case Study in Humanitarian Advocacy*, THE THOMAS J. WATSON JR. INSTITUTE FOR INTERNATIONAL STUDIES OCCASIONAL PAPER NO. 42, 59 (2000).

together to work toward achieving a common goal. Joseph Shapiro explains the importance of these connections in *No Pity: People with Disabilities Forging a New Civil Rights Movement*:

> There were groups representing all the major disabilities, including spinal cord injuries, deafness and visual handicaps, mental retardation and mental illness, as well as those for newer or less well-known conditions, such as AIDS, Tourette's Syndrome, and Chronic Fatigue Syndrome. To win passage of ADA disabled people had to forge historic alliances not only among different disability groups and politicians, but with the professionals who had cared for them so long.[97]

In the same way the ADA process was both educative and transformative, an international disability rights treaty process has the potential to build productive relationships between various actors. For the American disability community, the current effort is an opportunity to reinforce and strengthen their domestic advocacy in fundamental ways.

An international campaign for a treaty allows civil society groups to have a voice and work for social change over time. The participation of civil society in, for example, women's human rights, child rights, the use of landmines, or the rights of landmine survivors, is paradigmatic of how well-coordinated and informed groups can work in concert to strengthen international law and, therefore, make it relevant to people's lives.[98] The experience of landmine survivors in the development of the Landmine Ban Treaty[99] is a striking example of successful networking and effective coalition-building.[100] Early drafts of the treaty were silent on the issue of assistance for those whose lives had been affected by the presence of landmines in their own communities. The well-orchestrated efforts of survivors themselves led to the inclusion of a

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[97] SHAPIRO, *supra* note 88, at 127.

[98] For more on the successful ingredients of international campaigns, see MICHAEL EDWARDS & JOHN GAVENTA, EDS., GLOBAL CITIZEN ACTION (2001); KECK & SIKKINK, *supra* note 77.

[99] Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-personnel Mines and on Their Destruction, 18 Sept. 1997, *entered into force* 1 Mar. 1999.

[100] Hubert, *supra* note 96, at 59.

provision in the treaty that requires States Parties to address assistance for survivors.[101] Absent the participation of landmine survivors in the treaty process, the resulting agreement would have remained focused on the weapons ban alone. The active participation of the disability community—and reliance on their experience and expertise by treaty drafters—in the adoption of a treaty on the rights of people with disabilities and, once it has entered into force, its implementation, will create important channels and focus for the linking of disability advocacy efforts at the local, national, and international levels.

There are interesting models from which the disability community may draw inspiration in seeking to build coalitions to participate in the drafting of a treaty and to oversee its long-term implementation.[102] Most recently, particularly well-coordinated and successful international networks were established to steer civil society initiatives relating to child soldiers, climate change, and persistent organic pollutants.[103] Experience in engaging with the international human rights mechanisms led organizations concerned with torture to form a coalition in which their commonality is recognized and varying approaches are seen to be complementary and mutually reinforcing. Thus, the Coalition of International Non-Governmental Organisations Against Torture (CINAT) brings together six groups, of which one is engaged in pursuing legal remedies for redress,[104] two are engaged in individual work to provide direct assistance to torture

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[101] Article 6(3) of the Landmine Ban Treaty states the following:

> Each State Party in a position to do so shall provide assistance for the care and rehabilitation, and social and economic reintegration, of mine victims and for mine awareness programs. Such assistance may be provided, inter alia, through the United Nations system, international, regional or national organizations or institutions, the International Committee of the Red Cross, national Red Cross and Red Crescent societies and their International Federation, non-governmental organizations, or on a bilateral basis.

[102] Degener & Quinn endorse the call for strengthening civil society in the form of disability-focused coalitions. DEGENER & QUINN, *supra* note 17, §12.6.

[103] *See, e.g.*, International Persistent Organic Pollutants Elimination Network <http://www.ipen.org>, Climate Action Network <http://www.climatenetwork.org>, Coalition to Stop the Use of Child Soldiers <http://www.child-soldiers.org>.

[104] Redress—Seeking Reparation for Torture Survivors, at <http://www.redress.org>.

survivors,[105] one develops materials to aid the use of international mechanisms,[106] and two are primarily concerned with campaigning and monitoring State violations.[107]

In addition to providing unique opportunities to ensure that the voices of people with disabilities and their allies are heard in the drafting of an international convention, the treaty process can fulfill an important capacity-building role for all those actors engaged in it. Until now, most disability NGOs have not developed the capacity to enable them fully to engage existing international human rights mechanisms. Nor have they taken full advantage of opportunities to contribute to monitoring, reporting, and other activities of human rights institutions that complement and enhance domestic advocacy.[108] The treaty-making process constitutes a period of development for all actors (particularly NGOs) to expand their capabilities in a number of areas essential to their future work. The preparation period allows NGOs to learn human rights framework advocacy strategies and appreciate how the international human rights standards and mechanisms may be used to effect change at local, national, regional, and international levels. Equipped with this knowledge, organizations are then better prepared to participate in the following activities: (i) monitoring and surveillance of human rights problems; (ii) notification of emergency situations; (iii) human rights training and dissemination of information to their allies and the general public about human rights standards and their violations; (iv) reporting of human rights abuses to State and international bodies (treaty-monitoring and otherwise); (v) participation in international human rights litigation; and (vi)

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[105] International Rehabilitation Council for Torture Victims (IRCT) at <http://www.irct.org>, and World Organisation Against Torture (OMCT) at <http://www.omct.org>.

[106] Association for the Prevention of Torture (APT), at <http://www.apt.ch>.

[107] Amnesty International (AI) and the International Federation of Action by Christians for the Abolition of Torture (FIACAT).

[108] DEGENER & QUINN, *supra* note 17, §12.6. Special Rapporteur on Disability, Bengt Lindqvist, has stated that "to develop a disability dimension in the present monitoring system is a project that could be started with short notice and bring results fairly soon." *Summary Report of a Conference on the Theme: "Towards a United Nations Convention on the Human Rights of Persons with Disabilities,"* organized by the Department of Foreign Affairs of Ireland, the National Disability Authority and the Irish Human Rights Commission, Royal Hospital Kilmainham, Dublin, Ireland, February 26, 2002, at 30. (The Web site of the Special Rapporteur is available at <http//:www.disability-rapporteur.org>.)

engaging in constructive dialogue with governments and international organizations.[109] These activities both enhance and are enhanced by advocacy efforts already practiced by the disability community within the United States and elsewhere.

In sum, the process of developing an international human rights treaty for people with disabilities presents vital opportunities for stakeholders. These opportunities will be compromised, however, if the treaty-drafting process is unduly rushed. The doctrine adopted by the 1999 Interregional Seminar on International Standards on Disability in Hong Kong, supports the use of a fully participatory approach to developing a comprehensive treaty on the human rights of people with disabilities.[110] Haste in this important endeavor would not only compromise the form and content of the instrument itself but would also attenuate the capacity and coalition building afforded by the treaty-making process.

B. Promoting Institutional Shifts through the Adoption of an International Convention on the Rights of People with Disabilities

People with disabilities are indeed entitled to the same human rights accorded to all human beings in the Universal Declaration of Human Rights, the International Covenants on Civil and Political Rights and Economic, Social and Cultural Rights, and other international instruments.[111] The international institutions that stand to promote their rights and improve their lives, however, have not adequately integrated disability into their activities and programs.[112]

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[109] Julie Mertus, *From Legal Transplants to Transformative Justice: Human Rights and the Promise of Transnational Civil Society*, 14 AM. U. J. INT'L L. & POL'Y 1335 (1999).

[110] *See* Theresia Degener, *International Disability Law—A New Legal Subject on the Rise: The Interregional Expert's Meeting in Hong Kong*, 14 BERKELEY J. INT'L L. 180-195 (1999); Report of the Interregional Seminar and Symposium on International Norms and Standards Relating to Disability, Hong Kong, China, 13-17 Dec. 1999 (draft).

[111] Universal Declaration of Human Rights, *supra* note 38; International Covenant on Economic, Social and Cultural Rights, *supra* note 41; International Covenant on Civil and Political Rights, *supra* note 40. All three documents are available from the University of Minnesota Human Rights Library, at <http://www1.umn.edu/humanrts/instree/auob.htm>.

[112] For recommendations regarding the mainstreaming of disability, see DEGENER & QUINN, *supra* note 17, §12.1-12.4.

That is so notwithstanding directives issued in such documents as the Vienna Declaration of the 1993 World Conference on Human Rights, which stresses that the rights of people with disabilities do indeed form part and parcel of modern international human rights law.[113] The persistent marginalization of disability as a human rights concern holds true for intergovernmental organizations within the United Nations system as well as for international non-governmental organizations, including human rights organizations. Experience in other human rights spheres demonstrates how effectively an international human rights convention, with adequate awareness raising and support, can prompt fundamental institutional shifts that integrate human rights concerns into policy guidelines and operations. The need for such institutional change in the context of disability is clear. The active participation of the disability community in the drafting and implementation of an international convention on the human rights of people with disabilities will help to make this change a reality.

i. The UN Human Rights System

Within the very international human rights system that is designed to promote and protect human rights for all, the rights of people with disabilities are relegated to the periphery where they receive inadequate attention and resources. For example, the UN Program on Disability is housed *not* in the UN human rights sphere proper, but in the social development sphere. Currently, fewer than five people are devoted to servicing the office, half the number allocated to the office at the height of the UN Decade on Disability. As a practical matter, disability is addressed by the Department for Economic and Social Affairs (DESA), Division for Social Policy and Development,[114] and the UN Program on Disability sits in New York. Thus, the main UN office concerned with the lives of people with disabilities is several thousand miles away from the core UN human rights machinery in Geneva, where the whole

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[113] The Vienna Declaration provides that "all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities" and goes on to state that The World Conference on Human Rights calls on governments, where necessary, to adopt or adjust legislation to ensure access to these (life, welfare, education, work, living independently, and active participation in all aspects of society) and other rights for disabled people. Vienna Declaration and Program of Action, World Conference on Human Rights, Vienna, 14-25 June 1993, ¶ 63, U.N. Doc. A/CONF.157/24.

[114] For information on this program, see <http://www.un.org/esa/socdev/enable>.

structure for servicing and monitoring human rights treaties is located and where human rights policy makers and core resource centers are based. No focal point on disability exists within the UN Human Rights Centre, and, in addition, within the Office of the High Commissioner for Human Rights, disability is only one among a number of thematic issues that is handled by one or two staff members on a regular basis, but only as part of a larger portfolio of work.[115]

This institutional placement of disability outside the UN human rights framework has led to a marginalization, which is reflected in the work of UN treaty-monitoring bodies as well as other human rights mechanisms. The study shows that treaty-monitoring bodies, though mandated to take into account the extent to which specific treaty obligations are relevant for people with disabilities, have nonetheless failed to do so in any consistent and ongoing fashion. The situation is certainly not helped by the fact that disability organizations, unlike groups addressing the rights of women, racial minorities, torture survivors, children, and others, have not had the capacity-building experience of working within UN institutions through participation in the drafting and monitoring of a treaty specifically addressing their rights.

Past experience demonstrates that the centering of an issue within the UN human rights system draws attention to, and channels financial resources into, particular human rights initiatives. Absent such centering, governments, international organizations, and foundations have neglected to divert extensive resources to these initiatives. Leading up to and following major international conferences (Vienna and Beijing), major US foundation grants on projects relating to women's human rights and violence against women were increased from 11 totaling $241,000 in 1988 to 68 totaling $3,247,800 in 1993.[116] More fundamentally, the encapsulation of core human rights principles in one instrument will lessen the burden disability organizations face in having to selectively address their concerns within the disparate and decentralized treatment of disability in the current human rights system. That is not to say that instruments and mechanisms addressing disability should be ignored on the adoption of a new treaty, but that the

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[115] The study by Degener & Quinn recommends, among other things, that at least one staff person should be assigned to work on disability in human rights issues in a full-time position within the Office of the High Commissioner of Human Rights. DEGENER & QUINN, *supra* note 17, §12.3.

[116] KECK & SIKKINK, *supra* note 77.

treaty and its monitoring mechanisms will enhance the system so that disability receives a more focused and efficient treatment within the United Nations as a whole.

Furthermore, a specific treaty on international disability rights will establish a central institution for monitoring compliance with treaty obligations and channeling attention, expertise, funding, and time into compliance mechanisms.[117] The reporting mechanism created by an international treaty will establish an ongoing dialogue between governments, intergovernmental organizations, and civil society. Countries will be required to report on specific measures taken to comply with obligations, and disability organizations and human rights organizations will have the opportunity to present their own "shadow" or alternative reports that will expose weaknesses in State reporting or supplement reporting gaps. Human rights NGOs have created guidelines for alternative reporting to UN bodies that should inform disability advocacy strategies.[118] This State-reporting and parallel NGO shadow-reporting process is itself capacity building. Treaty-mandated meetings of the States Parties and regular meetings of specialized intergovernmental agencies within the UN human rights system will provide consistent and ongoing opportunities for disability organizations to draw attention to the issues they seek to influence and alter governments' perceptions of the costs and benefits associated with inaction.

ii. The UN Specialized Agencies and Development Institutions

The structural marginalization of disability within the United Nations is paralleled in its specialized agencies where disability tends to be treated as a "social protection" issue. A paradigmatic example of this institutional mischaracterization and frequent disregard of disability

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[117] Monitoring of the implementation of the UN Standard Rules relies upon the use of a Special Rapporteur, who reports to the Commission on Social Development. The Special Rapporteur is appointed every three years and so there is a marked lack of permanency in this particular monitoring model. Additionally, there is no mandatory State reporting system in place.

[118] *See, e.g.*, Association for the Prevention of Torture (APT), APT Guidelines for National NGOs on Alternative Reporting to UN Bodies, Including the Committee Against Torture (APT, 2000), available at <http://www.apt.ch/cat/guidelines.html>

is provided by the International Fund for Agricultural Development (IFAD).[119] IFAD is the primary UN agency whose mission is to work with the poorest populations in rural areas of developing countries to eliminate hunger and poverty; enhance food security; raise productivity and incomes; and improve the quality of life through improved access to productive resources and empowerment. On its Web site is an informational page titled "Who are the Poor?" in which IFAD sets forth its categorization of the rural poor in its operational regions of the world and purports to provide an "overview of the location and types of poor people." Included are (i) displaced people; (ii) female-headed households; (iii) indigenous people; (iv) scheduled castes and tribes; (v) wage laborers and landless people; (vi) artisinal fishermen; (vii) pastoralists; (viii) small holder farmers; and (ix) rain-fed farmers. Notwithstanding its proclamation that "[k]nowing and understanding the poor is as important as understanding poverty," people with disabilities are excluded from IFAD's categorization of the rural poor.[120] Significantly, gender concerns are a pivotal element of IFAD's poverty-alleviation strategy and agenda, signaling the impact of the international women's human rights movement in the operations of development institutions.

It should be noted that some international organizations have responded positively to disability awareness-raising initiatives. For example, in response to the Asian and Pacific Decade of Disabled Persons,[121] the Food and Agriculture Organization (FAO) introduced pilot programs in Thailand and Cambodia for disability-centered farming.[122] Although such programs are encouraging, the lack of institutional commitment to disability inclusion, reflected on the policy level, means that these positive steps occur occasionally and sporadically.

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[119] One of four hits in a disability word search on the Web page included references to the disability not of persons, but of sloping agricultural land. In a word search for both "women" and "gender," there were more than the maximum of 200 hits for each term. *See* <http://www.ifad.org>.

[120] IFAD's definition of the poor is discussed in IFAD, RURAL POVERTY REPORT 2001: THE CHALLENGE OF ENDING RURAL POVERTY 22 (Oxford 2001). The report is also available at <http://www.ifad.org/poverty/index.htm>.

[121] For information regarding the Decade, see <http://unescap.org/decade/index.htm>.

[122] For information detailing FAO's activities in this regard, see <http://www.fao.org/waicent/faoinfo/sustdev/PPdirect/PPre0035.htm>.

Furthermore, even where disability does appear on the policy agenda consciousness of development organizations, implementation and practice may not reflect current thinking about disability and may serve to reinforce harmful stereotypes and inappropriate models of disability. Take, for example, the 1993 World Development Report of the World Bank that exposed a new effort to quantify the global burden of diseases and to develop a statistical measurement for the values of lives lived with a disability, all in support of an attempt to prioritize health needs. The measurement, Disability Adjusted Life Years (DALYs), focuses primarily on assessing the impact of disability in terms of years of burden and loss. Groce, Chamie, and Me characterize the effort as "dangerously out of step with current thinking about what constitutes a disability and what individuals with a disability have to contribute to society."[123]

At its core, DALYs defines the burden produced by a certain condition/disease as years lived with disability and years of life lost as a result of premature death. Disability is, under this narrow measurement, equated with ill-health. People with disabilities, therefore, represent a burden to their societies and enjoy a poor quality of life. In need of health care or rehabilitation, people with disabilities are a net drain on their societies. Additionally, Metts criticizes DALYs for failing to recognize that disability is also a function of social and environmental factors and for assuming that prevention of impairments is the exclusive strategy for addressing disability.[124] Given this view of disability reflected in DALYs, it is not surprising to find development experts imagining that disability is a "special" issue, worthy of attention only when extra resources are available, after the development needs of others are met. Statistical measurements linked to disability do have a role to play in development policy, and people with disabilities should be included in devising such tools to ensure that concerns of the social model of disability are reflected in the resulting indicators.

If history is any indication, the introduction of an international treaty on the human rights of people with disabilities, and the concomitant highlighting of disability issues, should prompt organizational responses akin to those that followed international efforts relating to gender. UN

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[123] Groce et. al., *supra* note 93.

[124] Metts, *supra* note 1, at 1-2.

agencies and organizations have intensified their focus on gender issues as a direct response to world conferences on women's human rights and the resulting media attention to human rights violations against women. Today, nearly every UN organization is involved in a process of "gender mainstreaming," according to which the organization either creates a gender focal point or integrates gender throughout all its programs.[125] Whereas gender units and women's projects are still somewhat marginalized, understaffed, and underfunded, they are permanent features of both governmental and non-governmental international organizations.

Likewise, the adoption of a treaty on the rights of people with disabilities might encourage the inclusion of a disability perspective in national foreign policy and assistance programs. At present, there are often no requirements that people with disabilities be included in programming or that any form of disability impact assessment be performed in relation to program design and implementation.[126] The incongruence of foreign assistance programming with national disability policies is a stark reminder of the fact that government agencies with special roles to play in allocating foreign assistance have yet to figure disability issues into their work in any consistent fashion. Although the UN Standard Rules embraces the concept of conditioning development aid programs to the achievement of equality goals, the message has not yet been received.

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[125] JULIE A. MERTUS, WAR'S OFFENSIVE ON WOMEN 103-110 (Kumarian Press 2000).

[126] It should be noted that the United States Agency for International Development (USAID) has articulated in its Policy Paper on Disability, a "commitment to pursue advocacy for, outreach to, and inclusion of people with physical and cognitive disabilities, to the maximum extent feasible, in the design and implementation of USAID programming." USAID Policy Paper on Disability, Sept. 12, 1997, available at <http://www.usaid.gov/about/disability/DISABPOL.FIN.html >. Specifically, it said the following:

> USAID's policy on disability is as follows: To avoid discrimination against people with disabilities in programs which USAID funds and to stimulate an engagement of host country counterparts, governments, implementing organizations and other donors in promoting a climate of nondiscrimination against and equal opportunity for people with disabilities. The USAID policy on disability is to promote the inclusion of people with disabilities both within USAID programs and in host countries where USAID has programs.

Policy Paper on Disability, Sept. 12, 1997, §1. The Policy Paper describes the USAID disability policy as "in part an effort to extend the spirit of ADA in areas beyond the jurisdiction of U.S. law," for the ADA does not apply to the non-US beneficiaries of USAID programs, making adherence to the policy essentially voluntary. *Id.*

iii. The Human Rights of People with Disabilities within Human Rights Organizations

The work of human rights organizations has not served generally to raise awareness about the human rights condition of people with disabilities, notwithstanding the application and relevance to people with disabilities of the human rights principles that inform the work of human rights groups. Their advocacy remains largely irrelevant with specific respect to disability as a human rights issue. Several factors are likely contributors to the neglect of people with disabilities from the work of non-governmental human rights organizations.

Staffing arrangements within such organizations do not include leadership roles for people with disabilities. Expertise regarding disability is largely insufficient. In addition, a survey of the main international human rights texts used in American law schools and international relations curricula do not address disability.[127] As an example, in the second edition of Henry J. Steiner and Philip Alston's leading textbook, *International Human Rights in Context*, "disability," "people with disabilities," and related terms are not in the index, in contrast to multiple entries for women, children, racial and ethnic minorities, and indigenous peoples, all of whom have chapters or major sections devoted to their specific human rights issues. The citation listing for the same text includes a reference to the 1975 Declaration on the Rights of Disabled Persons, but omits all subsequent international instruments on disability, including the 1993 UN Standard Rules. These patterns are repeated throughout the literature and in electronic resources on international human rights law and policy and no doubt contribute to the lack of capacity within human rights organizations to address disability in any ongoing and consistent manner.

The adoption of a treaty specifically addressing the rights of people with disabilities will secure a place for disability as a human rights issue to be considered by all major human rights organizations in their work. Although it will take time for disability to be successfully integrated into the work of human rights groups, such groups may be expected (and should be encouraged) to follow closely developments in the drafting process of an international treaty on disability

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[127] *See, e.g.*, HENRY J. STEINER & PHILIP ALSTON, INTERNATIONAL HUMAN RIGHTS IN CONTEXT LAW, POLITICS & MORALS (Oxford Uni. Press, 2d ed., 2000); LOUIS HENKIN, ET AL., HUMAN RIGHTS (Foundation Press 1999); FRANK NEWMAN AND DAVID WEISSBRODT, INTERNATIONAL HUMAN RIGHTS: LAW, POLICY AND PROCESS (Anderson, 2d ed., 1996); and THOMAS BUERGENTHAL, INTERNATIONAL HUMAN RIGHTS IN A NUTSHELL(West, 2d ed., 1995).

rights and to participate in coordination with disability organizations. This involvement should prompt reappraisals of how disability as a human rights issue is addressed in the highly influential monitoring and reporting work of human rights organizations. For example, Amnesty International and Human Rights Watch use a methodology and produce reports that are widely regarded as credible and thus have the power to inform human rights policies of governments, including the United States, which routinely cites to and relies upon their work in its own human rights reporting. In addition, the adoption of a legally binding treaty on the rights of people with disabilities will prompt coverage in international human rights literature, training, and curricula, which has tended not to be the case with regard to non-binding instruments on the rights of specific minorities. This should, over time, strengthen the internal capacity of non-disability-focused human rights groups to consider how their work relates to the rights of people with disabilities and, ideally, encourage a commitment to that focus through the hiring of disabled people. Such developments would be in keeping with the organizational and programmatic shifts that occurred as a result of international advocacy on other human rights issues.[128]

C. The Role of Legally Binding Obligations

A treaty would be significant in establishing beyond question that persons with disabilities are indeed subjects of international rights and protection. Whereas the human rights of people with disabilities are accounted for in scattered provisions of treaties and in more concentrated non-binding declarations and other instruments, they have not been unified and elaborated on in any unified international law treaty.

i. Creating Legal Accountability

The UN Standard Rules are not currently regarded as having attained binding legal force. They were drafted as statements of intent—guidelines to be followed where possible—but may attain the status of customary international law where a sufficient number of States both follow

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[128] For a study that details the incorporation of gender policies and guidelines into the operational and programmatic work of such aid institutions as UNHCR, CARE, and Catholic Relief, see MERTUS, *supra* note 125, at 103-110.

the Rules in their practice and come to regard them as legally binding. Their content does represent a significant departure from earlier instruments addressing the rights of people with disabilities in their embrace of a social model of disability. Still, they remain aspirational and have no binding force in respect of the governments that adopted them.[129]

The advantage of a treaty setting forth obligations on the rights of people with disabilities is that it will establish concrete obligations for government conduct that specifically address disability. A treaty will serve to define the specific application of human rights concepts to people with disabilities and assist governments by providing an anchor for and informing the interpretation of general human rights principles. In addition, a treaty will set concrete standards for government conduct according to which States will guarantee specific human rights for persons with disabilities and undertake to bring internal legislation and policies in line with applicable human rights standards. Where such obligations are not met, the treaty constitutes an invaluable tool for disability advocates to push for change. When advocates in their home countries face obstacles in their advocacy efforts, international standards can support them and may be used to demonstrate that governments have already committed to recognizing certain rights. The extent to which international human rights standards can serve to support and strengthen grassroots advocacy initiatives will depend, of course, on the ability of the international human rights system to engage grassroots groups and demonstrate the relevance of human rights standards and mechanisms to their work on the ground. A concerted effort must be

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[129] Oscar Schachter has stated the following:

> Implementation and accountability are now regarded as essential elements of normative declarations, whether soft or hard law. Reporting, monitoring, transparency are emphasized by governments and international organizations. This indicates that institutional implementation rather than eventual customary law is the significant practical outcome of the non-binding normative resolutions. Governmental conduct is more likely to be influenced by the implementation procedures than by the claim that the norm has become customary law. The latter claim may assume some importance in a case before the International Court or another tribunal; but, outside of litigation, it would be very marginal to a government's decision on whether it should comply with a resolution of a non-binding character.

Oscar Schachter, *Recent Trends in International Law Making*, 12 A.Y.I.L. 1, 12-15 (1992), *cited in* Mac Darrow, *International Human Rights Law and Disability: Time for an International Convention on the Human Rights of People with Disabilities?* 3(1) AUSTL. J. HUM. RTS. 69, 88-89 (1996).

made, therefore, to convey the application of a wide range of international human rights practices to domestic advocacy initiatives.

ii. Reflecting Latest Developments in Disability Law and Policy

The existing disability-specific human rights instruments do not reflect the full range of human rights protections applicable to people with disabilities. The UN Standard Rules did not, even at the time they were drafted, incorporate all existing human rights principles applicable to people with disabilities. As an example, the UN Standard Rules do not contain a non-discrimination clause, nor do they address other core civil and political rights that are reflected in American constitutional and disability law and that have also attained the force of international customary law. The UN Standard Rules contain no provisions on the prohibition against torture and other forms of ill treatment, the prohibition against slavery and other forms of exploitative labor practices, or the right to life, human rights protections of profound relevance and importance to people with disabilities. While due process protections may be read into certain provisions of the UN Standard Rules, no explicit due process guarantees are expressed. Thus, the UN Standard Rules do not establish guidelines on the need for sign language interpreters in courts, nor do the Rules enumerate due process guarantees for the institutionalization of people with disabilities.[130] Furthermore, the UN Standard Rules do not explicitly address (i) multiple forms of discrimination facing particular groups of disabled people (such as women, religious and ethnic minorities, sexual minorities, and people living in poverty) and particular human rights concerns for those specific groups; (ii) children with disabilities; (iii) refugees and internally displaced people, particularly in crisis situations; (iv) the enforcement of human rights standards for people with disabilities within hospitals and institutions; and (v) people with HIV/AIDS. It should be noted that an international human rights treaty for people with disabilities would not replace wholesale the UN Standard Rules. Rather, such a treaty would

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[130] For example, in many instances, people with disabilities are often institutionalized without the benefit of any legal process to protect them against arbitrary detention. In cases where the law does provide for civil commitment or similar procedures, those laws are frequently ignored to the extent that the individual is arbitrarily deprived of all powers of decision-making. Rosenthal, *supra* note 18, at 69.

instead act to complement and reinforce the Rules, providing greater opportunity for their application.

A treaty specifically addressing the rights of people with disabilities provides an opportunity to identify specific practices that endanger the well-being and enjoyment of human rights by persons with disabilities. In the same way the 1995 World Conference on Human Rights recognized violence against women as a war crime, a treaty can serve to identify egregious practices against people with disabilities that have not attracted the attention of the international community. These practices include, for example, the institutionalization of people with disabilities in degrading and dehumanizing conditions, involuntary psychiatric procedures, and domestic violence against people with disabilities.[131] This lack of attention to egregious practices is significant given the virtual disappearance of people with disabilities from current human rights monitoring. A treaty on the rights of people with disabilities will provide a legal, as well as moral and political, basis for the wider recognition and protection of the rights of people with disabilities, thereby increasing the likelihood of the development of methodologies and indicators for measuring human rights violations, something that has not occurred with regard to the UN Standard Rules and other instruments relating to disability.[132]

iii. Prompting Shifts in National Laws and Policies

In accordance with their obligations, States must ensure that the principles embodied in treaties to which they are parties are given effect within the domestic legal order, and this can prompt the development of new legislation. Thus, for example, the US Endangered Species Act was enacted to implement provisions of the Convention on the International Trade in Endangered

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[131] For an account of international human rights reporting concerning involuntary psychiatric procedures, see World Network of Users of Psychiatry, Vancouver, Canada, (July, 2001), available at <http://www.wnusp.org/docs/hrposition.html>.

[132] *See, e.g.*, Limberg Principles on the Interpretation of the International Covenant on Economic, Social and Cultural Rights, U.N. Doc. E/CN.4/1987/17, Annex, *reprinted in* 9 HUM. RTS. Q. 122-135 (1987).

Species of Wild Fauna and Flora (CITES).[133] To give domestic effect to the provisions of an international treaty for the human rights of people with disabilities, a variety of methods exist by which international legal obligations may be implemented, including, but not limited to, the enactment of legislative measures.[134]

In addition to contributing to the development of domestic legislation, an international treaty can inform the work of domestic courts. The provisions of the treaty can not only serve as a guide in the interpretation of any specific implementing legislation, but the principles embodied in the treaty can also encourage the judicial development of other areas of domestic law. An international treaty on the human rights of people with disabilities might, for instance, provide the basis for invoking international law in a disability case before a national court. International law is cited with increasing frequency and effect in national courts, both in the United States and abroad. The United States has a significant body of case law wherein international standards have been either expressly invoked by individuals seeking a remedy for human rights violations or relied on to guide the interpretation of both state and federal laws.[135] In other instances, international standards may be used as a gap-filling device where domestic law is imprecise or undeveloped.

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[133] The Endangered Species Act was intended to be responsive to CITES, as well as other international treaties relating to the protection of endangered plants and animals. Endangered Species Act, 16 U.S.C. § 1531 et. seq. (1973).

[134] The method of translating international legal obligations into national law is dependent on the nature of the domestic legal system. For a straightforward account of this process, see *Report of the United Nations Consultative Expert Group Meeting on International Norms and Standards relating to Disability*, Berkeley, California, pp. 20-24 (December 8-12, 1998).

[135] *See, e.g.*, Filartiga v. Pena-Irala, 630 F.2d 876 (United States Court of Appeals, Second Circuit, 1980); Lareau v. Manson, 507 F. Supp. 1177, 1193 n. 18 (D. Conn. 1980) (using the UN Standard Minimum Rules for the Treatment of Prisoners as a guide to the interpretation of US law). For more on the role of international law in US courts, see generally JORDAN J. PAUST, INTERNATIONAL LAW AS LAW OF THE UNITED STATES (Carolina Academic Press 1996); Ralph Steinhardt, *Recovering the Charming Betsy Principle*, 94 AM. SOC'Y. INT'L L. PROC. 49 (2000); Ralph Steinhardt, *Fulfilling the Promise of Filartiga: Litigating Human Rights Claims Against the Estate of Ferdinand Marcos*, 20 YALE J. INT'L L. 65 (1995).

VI. Adopting an International Convention on the Rights of People with Disabilities: Issues and Concerns

The current effort to secure the adoption of an international treaty on the rights of people with disabilities has much to offer. As discussed above, the most significant advantages include (i) providing an immediate statement of international legal accountability regarding disability rights; (ii) clarifying the content of human rights principles and their application to people with disabilities; (iii) providing an authoritative and global reference point for domestic law and policy initiatives; (iv) providing mechanisms for more effective monitoring, including reporting on the enforcement of the convention by governments and non-governmental organizations, supervision by a body of experts mandated by the convention, and possibly the consideration of individual or group complaints under a mechanism to be created by the convention; (v) establishing a useful framework for international cooperation; (vi) providing a fair and common standard of assessment and achievement across cultures and levels of economic development; and (vii) providing transformative educative benefits for all participants engaged in the preparatory and formal negotiation phases and for the public as countries consider ratification of the convention. There are, however, challenges associated with launching yet another treaty initiative. These challenges include (i) strengthening the capacity and political will of people with disabilities and their representatives to participate fully and effectively in what is sure to be a lengthy coalition-building effort and international negotiation process; (ii) ensuring the constructive participation of the United States in international negotiations for a treaty; and (iii) overcoming growing "treaty fatigue" among governments and other actors with regard to multilateral treaty initiatives.

A. Strengthening the Advocacy Capacity of People with Disabilities and their Allies

Previous efforts to advance the human rights of people with disabilities through the adoption of a human rights treaty have failed not only partially on account of governmental disinterest but also as a result of the lack of mobilization and awareness-raising by people with

disabilities to build support for such a proposal.[136] A strong and fully mobilized coalition representative of the full range of people with disabilities and disability organizations is necessary in order to secure the adoption of a treaty that advances the human rights of *all* people with disabilities, including the most marginalized and oppressed sub-groups. In addition, without creating a well-coordinated global coalition with strong leadership by people with disabilities, it will be difficult for the disability community to take full advantage of their participatory role in the treaty process, which is, in itself, an immensely educative and galvanizing process for all involved. Risks are therefore associated with having an international process that is not fully participatory or one in which only some disability groups or mainstream human rights organizations purport to speak for all people with disabilities.

An additional risk to be assessed in the context of engaging in a treaty process is the relative degree of consensus within the broad disability community as to the key elements of a coherent and focused international campaign. Absent consensus on some core components of the treaty among a broad-based coalition of the global disability community, the effectiveness of non-governmental participation would be compromised by division and the resulting agreement may disappoint. Even assuming consensus regarding major issues, it will be crucial for the non-governmental community to be highly coordinated and to develop effective tools with which to advocate for acceptable treaty language and strong institutional mechanisms for compliance. In this regard, the highly developed participatory strategies of earlier successful campaigns will serve as useful models for the disability community.[137]

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[136] There were two early efforts within the United Nations to build support for the drafting of an international treaty on the rights of people with disabilities. In 1987, the Global Meeting of Experts to review the Implementation of the World Programme of Action concerning Disabled Persons was convened at the mid-point of the UN Decade of Disabled Persons and recommended that the UN General Assembly convene a conference to draft an international convention on the elimination of all forms of discrimination against persons with disabilities. Draft agreements were in fact prepared by Italy (U.N. Doc. A/C.3/42/SR.16 (1987)) and Sweden (U.N. Doc. A/C.3/44/SR.16 (1989)) but were rejected by the UN General Assembly at its forty-second and forty-fourth sessions, respectively, mainly because of disinterest and treaty fatigue. For more on these efforts, see generally Bengt Lindqvist, *Standard Rules in the Disability Field, in* HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS 64-65 (Theresia Degener & Yolan Koster-Dreese, eds., 1995).

[137] For some excellent examples of practical tools used by other international campaigns to guide their effective participation in international treaty and conference processes, see SHARYLE PATTON AND KAREN PERRY, A MANUAL FOR NGO PARTICIPANTS IN THE PERSISTENT ORGANIC POLLUTANTS (POPS) INTERGOVERNMENTAL NEGOTIATING COMMITTEE (INC) PROCESS (1999); International Women's Tribune Centre, *Get Ready! Connecting Beijing to*

B. Ensuring Constructive U.S. Participation

Of major concern to disability organizations worldwide will be securing the constructive participation of the United States in negotiations for the adoption of an international treaty on the rights of people with disabilities and, thereafter, ensuring signature and ratification of the treaty by the United States. Regrettably, the United States has the poorest record of ratification of human rights treaties among all industrialized nations, having ratified only 3 of 26 international human rights treaties. This history bears the unmistakable imprint of resistance to the domestic application of human rights treaties in US courts during the 1950s, when many states had in place overtly discriminatory and racist laws.[138] Although the United States started out in a position of international leadership in the early international human rights movement, which included the participation of Eleanor Roosevelt and other Americans, Senator John W. Bricker of Ohio brought an abrupt end to this pioneering role in the early 1950s.[139]

During the early 1950s, Senator Bricker proposed an amendment to the US Constitution that would have made all treaties non-self-executing, meaning, among other things, that individuals would be unable invoke treaty provisions in US courts absent implementing legislation. The amendment would have made it extremely difficult for the United States to join

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Action at Home, 52 THE TRIBUNE—A WOMEN AND DEVELOPMENT Q. (November 1994). For some useful discussions of international campaign strategies and the activities of transnational advocacy networks respectively, see EDWARDS & GAVENTA, *supra* note 98; KECK & SIKKINK, *supra* note 77.

[138] *See* BUERGENTHAL, *supra* note 127; VERNON VAN DYKE, HUMAN RIGHTS, THE UNITED STATES AND WORLD COMMUNITY vi, 131-134 (1970).

[139] Indeed, from the early days of the American Republic, and continuing throughout our constitutional history, there have been numerous invocations of human rights concepts by American jurists and policymakers, expressed variously as the "rights of man," "rights of mankind," and "human rights." Alexander Hamilton stated in 1779 that "the sacred rights of mankind ... are written, as with a sunbeam, in the whole volume of human nature ... and can never be erased or obscured by mortal power." ALEXANDER HAMILTON, THE FARMER REFUTED (N.Y. 1775), *quoted in* PAUST, *supra* note 135, at 167.

human rights treaties, thus helping to preserve racist state legislation.[140] Fortunately, President Eisenhower was successful in defeating the Senator's amendment, but success came at a cost. In order to defeat the amendment, the administration promised not to accede to any international human rights treaties.[141] This policy of non-accession was dropped by successive administrations, and most have long since forgotten Senator Bricker's successful campaign to ward off US participation in international human rights treaties and its overt connection to racist law and policies that stood to be set aside by international standards of non-discrimination.[142]

Bricker's legacy remains, though, and may still be discerned in well-worn and oddly unquestioned justifications for US non-participation in human rights treaties based on the complexities of our federal system, the notion that human rights are an exclusive concern of domestic jurisdiction, and the fact that the US Constitution does not permit the use of the treaty power for regulation of such matters, the potential for conflict between treaty obligations and the Constitution, and the like. As inaccurate as these now reflexive responses are in the opinion of a host of highly respected international law scholars and practitioners,[143] they remain serious obstacles in securing the participation of the United States in virtually any multilateral treaty effort, and human rights treaties in particular. The fact remains, however, that the rest of the world has much to gain by the meaningful participation of American disability groups and policy makers in supporting a human rights treaty that will help foster domestic law changes around the

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[140] The most important language in the amendment stated that "A treaty shall become effective in the United States only through legislation which would be valid in the absence of treaty." In other words, under the amendment Congress would not be able to use a treaty to implement legislation that it would normally be powerless to introduce. Louis Henkin, *U.S. Ratification of Human Rights Conventions: The Ghost of Senator Bricker*, 89 AM. J. INT'L L. 341, 348 (1995).

[141] *Id.* at 348-49.

[142] *See* D. TANANBAUM, THE BRICKER AMENDMENT CONTROVERSY: A TEST OF EISENHOWER'S POLITICAL LEADERSHIP (1988); Kaufman & Whiteman, *Opposition to Human Rights Treaties in the United States Senate: The Legacy of the Bricker Amendment*, 10 HUM. RTS. Q. 309 (1988).

[143] *See, e.g.*, BUERGENTHAL, *supra* note 127, at 284-298; Louis Henkin, *The Constitution, Treaties and International Human Rights*, U. PA. L. REV. 1012 (1968); Remarks of Professor Louis B. Sohn before the 1979 Senate Hearings on International Human Rights Treaties (S. Comm. For. Rel., 96th Cong., 1st Sess.), where Professor Sohn stated that the "fears [of the United States regarding human rights treaties] have been exaggerated and that it is simply part of the general feeling that the United States knows better about various things and therefore should not be subject to other peoples' judgments." STEINER & ALSTON, *supra* note 127, at 1037.

world similar to what the ADA has done to shape disability law and policy in the United States. The American disability community likewise has much to gain by participating in the rich, educative process to draft a treaty on the rights of people with disabilities. The challenge will be to ensure that the United States remains constructively engaged throughout the process to draft a treaty and works in close partnership with disabled people and their representative organizations.

C. Combating Treaty Fatigue

The prospect of securing the meaningful and universal participation of States in another international human rights treaty may seem especially daunting at a time when many speak of "treaty fatigue" and "treaty congestion." To be sure, there are challenges associated with any proposal for a new international agreement. The national reporting mechanisms (requiring States Parties to report on their implementation of obligations) frequently receive reports that are inaccurate, incomplete, or late. In many instances, the reports are not submitted at all. Even when adequate reports are received, under-resourced treaty-monitoring bodies may be forced into hasty and superficial reviews of the reports. The increase in the number of treaties with reporting requirements in the human rights treaty context (and international environmental realm) have led to concerns about the increasingly burdensome proliferation of reporting requirements, hence the term "treaty fatigue." With some countries unable to cope with existing reporting requirements for the treaties to which they are party, the prospect of securing their meaningful participation in additional treaty mechanisms may seem remote.

Notwithstanding such challenges associated with participation in international human rights agreements, devices are available to promote timely reporting and procedures to enhance the review of State reports from which lessons can be drawn. In an effort to respond to difficulties with meeting reporting requirements, international environmental regimes have introduced more specific reporting guidelines, providing precise reporting deadlines, permitting the consideration of non-official sources of information (in the event that a State fails to meet its deadline), and providing financial and technical assistance to States in the preparation of their

reports.[144] Some human rights treaty-monitoring bodies have likewise introduced guidelines to enhance the effectiveness of reporting.[145] By using such procedures, a human rights treaty for people with disabilities could ensure that the benefits of reporting mechanisms are gained, without placing undue burden upon States Parties.

One final response to concerns about growing treaty fatigue is that the process of adopting a convention on the rights of people with disabilities will generate an increase in knowledge and understanding of disability as a human rights issue that no current institutional structure has been able to provide. A treaty specifically addressing the rights of people with disabilities stands to contribute to the diversity of knowledge within international human rights institutions, as well as other settings, in a way that has not yet occurred in the context of disability. In turn, disability organizations will forge alliances and understand their mission within the larger context of human rights. Given the size and breadth of the human rights concerns of people with disabilities, the case for a separate treaty is especially compelling.

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[144] For example, the Montreal Protocol provides specific reporting timelines for States Parties, and it also permits "Member States of a regional economic integration organization" to provide some of the reports on a regional organization basis, rather than individually (Art. 7). Montreal Protocol on Substances that Deplete the Ozone Layer, 16 September 1987, U.K.T.S. 19 (1990); Cm. 977; 26 I.L.M. (1987) 1550; 17 E.P.L. (1987) 256. The Convention to Combat Desertification also permits States Parties to provide "a joint communication on measures taken at the subregional and/or regional levels," (Art. 26(4)), and in addition it provides for the provision of technical and financial support to developing countries, to better enable them to meet their reporting requirements (Art. 26(7)). Convention to Combat Desertification in Those Countries Experiencing Drought and/or Desertification, Particularly in Africa, 17 June 1994, 33 I.L.M. (1994) 1332-82.

[145] *See, e.g.*, Committee Against Torture, guidelines regarding the form and content of periodic reports to be submitted by States Parties under Article 19, paragraph 1 of the Convention, adopted by the Committee at its 85th meeting (sixth session), on 30 April 1991, and revised at its 318th meeting (twentieth session), on 18 May 1998, U.N. Doc. A/53/44, Annex VI, 16 Sept. 1998, available at < http://www.unhchr.ch/tbs/doc.nsf >; Revised General Guidelines Regarding the Form and Contents of Reports to be Submitted by States Parties Under Articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights, U.N. Doc. E/C.12/1991/1, 17 June 1991, available at < http://www.unhchr.ch/tbs/doc.nsf>.

VII. Recommendations and Future Directions

Policy makers and disability organizations should be prepared for sustained action over a long period of time to bring about durable improvements in the human rights condition of people with disabilities throughout the world. International and domestic polices on disability must aim to break down the barriers to full participation in society by people with disabilities through work at different levels using complementary approaches. An effective strategy must address, at a minimum, the following issue areas.

A. Principles for Participation in the Process of Drafting an International Convention on the Rights of People with Disabilities

International law and practice support the participation of people in all decision-making processes in which their interests are affected. Unfortunately, many of the past efforts in international law and policy-making concerning people with disabilities have not adequately provided for the meaningful participation of people with disabilities. The following principles must drive the current initiative to draft an international convention on the rights of people with disabilities:

- The process of drafting any new treaty needs to be open-ended, inclusive, and representative of the interests of people with disabilities, including the most marginalized sectors of the disability community.

- People with disabilities must be principal participants in the drafting of any new treaty at all stages in the negotiation process.

- All expert meetings associated with the development of international law and policy must be organized to include the participation of architects, lawyers, policy analysts, engineers, and other relevant professionals with direct personal experience with disability.

The process by which a convention on the rights of people with disabilities is drafted should be broadly participatory throughout the preparatory and conference phases, ensuring meaningful representation of the disability community, including the most marginalized groups of people with disabilities. The conference and preparatory phases of an international convention should be coordinated in Geneva, where the UN human rights system is based.

B. Addressing Attitudes and Perceptions of People with Disabilities in Law and Policy Initiatives

Actors should be sure to participate in self-evaluation to ensure that their own policies and initiatives do not inadvertently serve to perpetuate the oppression and discrimination of people with disabilities. Accordingly, the insights of the social model of disability must be considered. This applies to all actors (governmental, non-governmental, and individual) engaged in disability policy decision-making.

Any law and policy initiative that addresses the human rights of people with disabilities, whether national or international, should reflect the social model of disability that now frames current thinking about disability.

C. Raising Awareness and Building the Capacity of Actors to Address the Human Rights of People with Disabilities

Potential participants in a treaty-making process must recognize and capitalize on the opportunities for capacity-building and awareness-raising concerning disability as a human rights issue. Failure to do so will result in (i) the continued under-use by the disability community of existing human rights mechanisms and inadequate use and development of mechanisms established by a new treaty; and (ii) under-use by decision-makers of the disability community as a source of critical input on issues that affect people with disabilities. Participants should resist the urge to rush the treaty process. The following activities, *inter alia*, should be regarded as central to any human rights strategy embarked on by disability organizations:

- Promoting public education and awareness about the human rights condition of people with physical and mental disabilities.
- Use of existing UN human rights treaty processes.
- Engagement by disability organizations with regional human rights systems.
- Monitoring of, and reporting on, human rights violations against people with disabilities.
- Encouraging governments to support human rights education programs for people with disabilities as a part of their response to the UN Decade for Human Rights Education.

D. Principles to Support Full Participation in Society by People with Disabilities

The participation of people with disabilities in decisions that concern them, and in bodies that are relevant to their lives, is a fundamental principle that must be reflected in international law and policy. People with disabilities, as is common to many minority groups, are often politically invisible. People with disabilities must be politically represented within public institutions, and their representatives should be accountable to people with disabilities, empowered to represent their interests and competent to communicate their interests effectively. The following principles, among others, need to be recognized and reflected in the development of new national and international instruments:

- The treaty should embody the principle of non-discrimination and should recognize and seek to counter multiple forms of discrimination against people with disabilities.
- Political representation and participation in decision-making by people with disabilities should feature prominently in an international treaty.
- Due process protections for people with disabilities, not featured at all in the UN Standard Rules, should receive explicit and detailed coverage.

Consistent with principles of due process and participation under international human rights law and the UN Standard Rules, all governmental and non-governmental discussions concerning human rights must provide for the meaningful participation of people with disabilities. Moreover, any fora in which international human rights experts or other

professionals are brought together to discuss the rights of people with disabilities must include the participation of professionals who themselves have personal experience with disability.

E. Human Rights Principles and Spheres of Human Rights Protection for People with Disabilities

International human rights principles found in existing treaties must be read along with other international human rights documents to identify the *full* range of human rights to which people with disabilities are entitled under existing international human rights law. In addition, models of national disability legislation, including, but certainly not limited to, the Americans with Disabilities Act, should be consulted to identify areas in which existing international human rights law on disability might be further developed. The following human rights principles and spheres of human rights protection, reflected in international human rights law, must receive coverage in any treaty to be developed on the human rights of people with disabilities:

- Non-discrimination
- Stereotyping of groups
- Participation
- Right to life
- Freedom from torture and other forms of ill-treatment
- Slavery, servitude, and forced labor
- Survivor assistance
- Equality before the law
- Due process protections
- Rights of peaceful assembly and association
- Freedom of thought/opinion and information
- Political and public life
- Accessibility (to the built and natural environments, technology)
- Medical care/health/rehabilitation
- Employment/social security/income maintenance

- Education
- Culture and religion
- Recreation and sports
- Nationality/freedom of movement/refugees/internally displaced persons

Reference should be made to the full repository of international human rights standards in the development of an international convention.

F. A Strong Treaty-Monitoring Mechanism

The key to the successful implementation of a convention on the human rights of people with disabilities is the establishment within the framework of the convention of a strong monitoring mechanism. A committee that is adequately resourced and that consists of people with disabilities with relevant expertise is critical to the credibility, legitimacy, and efficacy of the treaty. The committee should be mandated to receive and act upon State reports on treaty implementation measures. In addition, the committee should be authorized to receive information from non-governmental organizations that are an important supplemental source of information regarding State implementation measures. Finally, a committee should have the power to receive and act upon State-to-State complaints as well as complaints originating from individuals or groups competent to represent people with disabilities.

G. Future Directions in Coalition-Building

Disability and human rights groups worldwide should work to raise awareness and support for the strengthening of existing human rights mechanisms and their capacity to acknowledge and address the human rights of people with disabilities. In addition, such groups should work collectively to promote the adoption of an international convention on the human rights of people with disabilities, so that all stakeholders are consulted. These efforts should include, at a minimum, the following:

- Coordination of efforts to engage with existing human rights treaty-monitoring bodies and other international and regional human rights processes.
- Development of consensus on core principles to be included in the treaty.
- Development of a tool-kit and other materials for outreach and education to be followed by wide dissemination in cooperation with disability organizations, for which there are ready models for adaptation from other international human rights contexts.

VIII. Conclusion

Although there exists a robust global human rights system, people with disabilities throughout the world still face substantial obstacles to the full enjoyment of their human rights and confront human rights abuses on a daily basis. An international convention on the human rights of people with disabilities would not only add much-needed content to the existing framework of international human rights law, but would also establish an institutional framework to monitor the global human rights condition of people with disabilities. In addition, there are positive transformative effects to be gained from the treaty-drafting process. Constructive engagement by the United States and the American disability and human rights communities will ensure that those engaged in promoting the human rights of people with disabilities possess the necessary capacity to further the human rights vision embodied in the treaty and the human rights system as a whole.

Appendix

Glossary of International Law Terms

To assist readers of this paper who may not be familiar with the terms of international law, the following is a brief glossary that explains some of the terms commonly referenced in international law. For a clear, accessible guide to international law and a more extensive discussion of some of the terms commonly used, see THOMAS BUERGENTHAL & HAROLD G. MAIER, PUBLIC INTERNATIONAL LAW 24 (West 2nd ed. 1990). For an additional widely referenced but more extensive treatise on international law, see MALCOLM N. SHAW, INTERNATIONAL LAW (Cambridge, 4th ed. 1997).

Accession—there will usually be a specified period of time during which States can become parties to a treaty/convention through a process of "signing" and "ratification." After this period of time has ended, States can typically become parties to a treaty/convention through a process of "accession," whereby they pledge to be bound to the terms of the treaty/convention, subject to any "RUDs" that they may have filed at the same time.

Adoption—once the text of an international document has been agreed on, it is said to have been "adopted." The legal significance of this adoption will depend on the nature of the document in question. Thus, non-binding UN General Assembly resolutions are "adopted," and binding treaties are likewise "adopted" following the end of a treaty negotiating process.

Convention/Treaty—*see* "Treaty," below. (For additional sources of law, *see* "Sources of law," below.)

Customary international law—customary international law refers to a rule or principle that is reflected in the practice or behavior of States and is accepted by them (expressly or tacitly) as being legally binding as a matter of international law. Thus, in order to identify whether a given

practice is indeed a rule of customary international law, one must examine whether the particular practice of States is general and consistent and occurs because States believe they are acting as a result of a legal obligation, as opposed to comity or courtesy. Although not all States need to engage in the practice before it is considered legally binding, there should be a uniformity of practice across the international community. States that have not engaged in the practice and have persistently (and consistently) objected (i.e., persistent objectors) to it since its emergence as a customary rule will not be bound by it. Conversely, States that do not engage in the practice but have failed to issue objections (i.e., become persistent objectors) will be bound by any rule of international customary law that develops. (For additional sources of law, *see* "Sources of law," below.)

Declaration— an "instrument" such as the Universal Declaration of Human Rights constitutes an aspirational document that sets forth assertions by a State (or States). Because of its aspirational nature, a "declaration" is not considered binding under international law unless its provisions become incorporated into customary international law, as has been the case with many of the provisions of the Universal Declaration of Human Rights. (*See* "customary law," above.)

Entry into force— mere "adoption" of a treaty/convention is not sufficient for the terms of that document to be fully binding on any States Parties. Instead, the treaty/convention becomes fully enforceable on States Parties once the treaty has "entered into force." Typically, a treaty/convention will specify how many States must become members before the treaty/convention "enters into force." If the specified number of States Parties is never reached, then the treaty/convention will never enter into force and be given full effect as a matter of international law.

General principles of law—general principles of law recognized by or common to the world's major legal systems are a source of international law. They are now relied on less frequently than other sources of international law, but may serve as important gap-filling devices, especially in cases related to procedural matters and problems of international judicial administration. In order

to determine the existence of a "general principle" of international law, a court will typically look to the laws that are included within States' municipal systems. (For additional sources of law, *see* "Sources of law," below.)

Instrument—this is a generic term frequently used to refer to an international document. The "instrument" in question may be either of a binding or non-binding character.

International Bill of Rights—this is the name given to the trio of documents that form the core of general human rights provisions. The "Bill" consists of the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights. While the two Covenants are legally binding international treaties/conventions, the Universal Declaration was adopted as a General Assembly Resolution and was therefore considered a non-binding, aspirational document at the time. It is now widely regarded as having attained the status of customary international law, in whole or at least in respect of some of its provisions.

International Covenant on Economic, Social and Cultural Rights—*see* "International Bill of Rights," above.

International Covenant on Economic and Social Rights—*see* "International Bill of Rights," above.

Jus cogens—this is a fundamental, peremptory norm of international law that is binding on all States, even if they object to it. An example of international laws that are regarded as jus cogens include the international prohibitions against torture, genocide, and the slave trade. These are crimes for which there is no defense, and that *all* States must undertake to prevent and punish. (For additional sources of law, *see* "Sources of law," below.)

Object and purpose—this constitutes the essential character of a document and it can typically be discerned from the title of the document and any preambular text. It is this "object and purpose" that States Parties must always ensure that they do not violate and that signatory States must respect unless/until they declare that they do not wish to "ratify" the treaty/convention and become full States Parties. In more recent times, the United States has adopted the unusual—and in one case rather dubious—practice of "unsigning" treaties.

Ratification—ratification constitutes the second and final stage at which a state typically becomes a member or "States Party" to a treaty/convention. Unless a process of "accession" is used to attain membership, a State will usually sign the treaty/convention and then send the document to its governing legislature for consideration. The actual process of ratification is governed by domestic laws, and so is different in each country. In the United States, a treaty is ratified by the President with the advice and consent of 2/3 of the Senate.

Reservations, understandings and declarations (RUDs)—although some treaties/conventions do not permit the filing of RUDs (ILO treaties typically do not permit such filings), most treaties/conventions will permit States to file RUDs at the time they ratify or accede to a treaty. RUDs are tools used by States to limit the scope of application of a treaty or to make clear how a State interprets some aspect of the treaty. For example, if a provision of a treaty will violate a State's domestic constitutional provisions, that State will usually file a "reservation" to the provision, so that the specified provision does not apply to the State and cannot be enforced against it. It should be noted that if the "reservation" contravenes the essential "object and purpose" of a treaty/convention, then the "reservation" will be invalid and the treaty/convention provision in question will usually still apply to the State. Whereas "understandings" and "declarations" do not exempt the application of treaty/convention provisions to a State, they do provide States with an opportunity to clarify how they believe a particular provision should be interpreted.

Resolution—this is a non-binding instrument that expresses the common interest of a group of States and is usually adopted under the auspices of an organ that is part of an international organization, such as the UN General Assembly. In most cases, there is no legal obligation to implement the terms of a resolution, but in some cases "resolutions" may have a quasi-legislative effect. Resolutions may, however, aid in the development of international law and may, over time, become part of "customary international law."

Signature—"signature" constitutes the first step for a State to become a party to a treaty. At this stage, the State is *not* bound to abide by *all* the specific provisions of the treaty/convention, even if the treaty/convention has "entered into force." Instead, the State is bound to abide by the "object and purpose" of the treaty. This level of obligation is maintained until the State either "ratifies" the treaty/convention (causing it to assume responsibility for all of the provisions for which it has not filed a "reservation") or sends notice that it is rejecting the treaty and has no intention of ever "ratifying" it (thus releasing it from any obligation to abide by the treaty/convention). The United States has recently "unsigned" two treaties that it had previously signed but not ratified.

Sources of law—Article 38(1) of the Statute of the International Court of Justice is perhaps the most authoritative statement of the sources of international law. The Article lists the following as the sources:

- International conventions, whether general or particular, establishing rules expressly recognized by the contesting states.
- International custom, as evidence of a general practice accepted as law.
- The general principles of law recognized by civilized nations subject to the provisions of Article 59, judicial decisions, and the teachings of the most highly qualified publicists of the various nations, as subsidiary means for the determination of rules of law.

For definitions and discussion of the sources listed by the ICJ Statute, *see infra*.

Standards—"standards" provide a guide for how States should act under certain circumstances. "Standards" may be expressed in non-binding instruments (such as the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities) or in binding instruments, such as treaties/conventions.

States Parties—this is a term used to denote a State that is a member of (or party to) a particular document or organization.

Treaty/Convention—the law of treaties is governed primarily by the 1969 Vienna Convention on the Law of Treaties (which came into force in 1980), as well as by customary law. Under Article 2 of the Vienna Convention, a "treaty means an international agreement concluded between States in written form and governed by international law, whether embodied in a single instrument or in two or more related instruments and whatever its particular designation." The fundamental characteristic of a treaty is that it is binding on the parties to it, and the terms of the treaty must be performed in good faith. Typically, States will become "States Parties" to a treaty by "signing" and "ratifying" the document. Alternatively, States may "accede" to the treaty through a process known as "accession." It should be noted that States will sometimes file "RUDs" at the time they join a treaty, which will serve to affect how the treaty is applied to that State. The treaty will usually specify how many States need to have become States Parties before the treaty "comes into force" and the terms of the treaty become enforceable. Binding, written international agreements may be referred to by numerous names, including treaty, convention, agreement, protocol, covenant, charter, statute, etc. (For additional sources of law, *see* "Sources of law," above.)

Universal Declaration of Human Rights—*see* "International Bill of Rights," above.

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the US Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts, and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other

officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the US government's official contact point for disability issues. Specifically, NCD interacts with the Special Rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the Americans with Disabilities Act. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of the ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
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